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# Spiritual Empowerment of Special Needs Families

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GEORGE FOX UNIVERSITY

SPIRITUAL EMPOWERMENT OF SPECIAL NEEDS FAMILIES

A DISSERTATION SUBMITTED TO  
THE FACULTY OF GEORGE FOX EVANGELICAL SEMINARY  
IN CANDIDACY FOR THE DEGREE OF  
DOCTOR OF MINISTRY

BY  
ANDREW LEON MEEKO

PORTLAND, OREGON  
JANUARY 2002



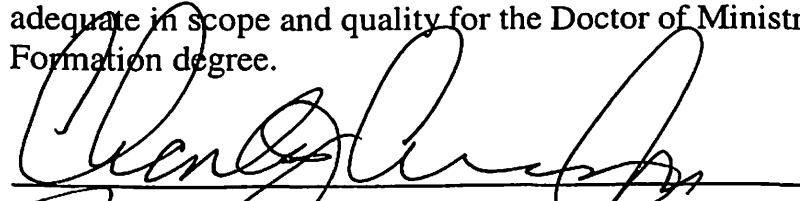
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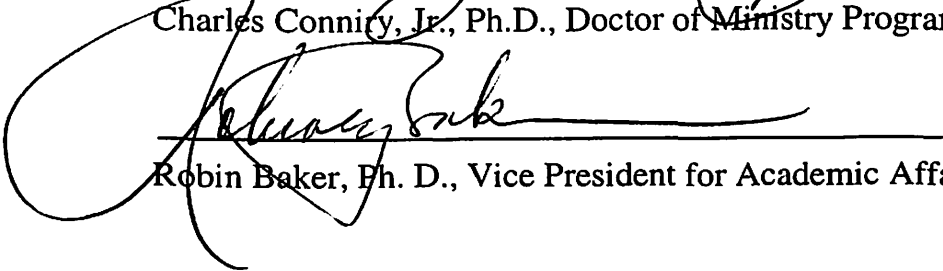
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**Presented by: Andrew Leon Meeko**  
**May 1, 2002**

We, the undersigned, certify that we have read this dissertation and approve it as adequate in scope and quality for the Doctor of Ministry in Leadership and Spiritual Formation degree.



Charles Conniry, Jr., Ph.D., Doctor of Ministry Program Director



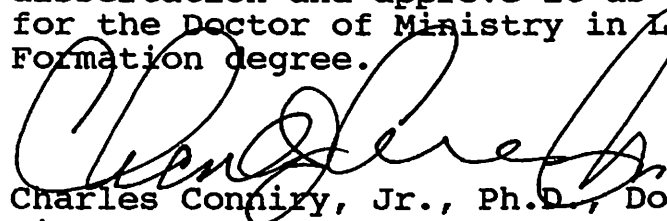
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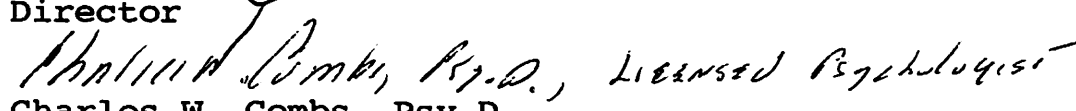
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Charles W. Combs, Psy.D.

To Sophia and to the special homes around the globe

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## Abstract

Families with children possessing disability face crushing challenges physically, economically, socially, emotionally, and spiritually. Sadly, most succumb to this onslaught and disintegrate. The tragedy of these families is only amplified in that they have the potential to influence lives, churches, and nations as perhaps no other entity can.

Chapter One focuses on understanding the tragedy of special needs families. The dehumanizing attitudes and denials of basic rights that handicap those with disability are examined. Chapter Two takes a closer look at the stresses and emotional whirlpools these families endure. Stress hardness and cohesion/control mechanisms of families are also considered in an attempt to grasp why some families are actually enriched through their struggle. Chapter Three examines the ancient approach of Spiritual Direction. This approach is presented as a means for helping the family members find their true selves, and the true God speaking at the center of their beings. There is particular emphasis on levels of prayer, the Three Ways, and the “dark nights.” Chapter Four is given to the recently evolved approach of Narrative Therapy, a field that presents a new direction in the therapeutic world. The particular value of the approach here is in its skepticism of the cultural norm and in the way it imparts freedom to a family to re-author its own reality. This approach encourages the unearthing of dormant abilities and resources. Chapter Five concludes the study by examining the similarities and differences of these two approaches as applied to the special needs family, as well as by exploring how they complement one another in ways that can help such families survive and even thrive.

The aim of this study is not to formulate a rubber stamp method of empowerment for these families, but rather to be true to the sense of mystery and curiosity in both approaches. The path for each family is viewed as uniquely matched to its personality and experience in God. Overall, disability is viewed as having the potential for immense good, both in deepening individual lives and in bringing renewal to global society.

PART 1  
UNDERSTANDING THE SYSTEM

CHAPTER 1  
A VIOLATED POTENTIAL

**Introduction**  
**One Little Girl**

Elizabeth stood silently by her mother in the foyer. With blond curls and a print dress, she was a darling four-year-old. But something was different. Her eyes protruded, even bulged, excruciatingly from her small skull. That is what most people would notice. They would never know of the countless surgeries she had endured since infancy. They would not know the name of the condition that had caused her to need them. They would not realize that she could not hear their voices when they spoke to her, for she was deaf as well. They would never grasp what goes on in her little heart, or in her family's heart. Perhaps, at best, they might see a girl to pity.

Sitting in the crowd that Sunday, I pondered the struggle of that petite girl and the mother who loved her so tenderly. Suddenly an image came to mind. Christ was present at church that day. Though thousands attended the worship service, many with fine attire, appealing faces, impressive lives, I saw Jesus at the back, with Elizabeth. There, he kneeled before her. The smile on his face and the glimmer in his eyes captivated her. They spoke silently together, signing with their hands. Out of all the thousands present that day, Jesus was with Elizabeth.

Objectively, however, what kind of future does Elizabeth have? The answer to that question depends on a number of things that are the subject of this paper, but if

Elizabeth is coming from the average home, the spiritually unempowered home, her future looks categorically grim.

### **The Challenge of Special Needs Family Systems**

Children with disability have a rough road to travel. They must battle not only the immense physical and emotional struggles that go along with their particular disability, but numerous other challenges as well. Many studies indicate that Elizabeth faces a greater potential for family turmoil, for parents divorcing, for domestic abuse, and for numerous socio-economic problems.

The implications of disability for each child, however, are by no means certain. Some researchers debate the meaning of data comparing the special needs family to the general population. Milton Seligman addresses this issue:

Based on our present state of knowledge, it is unrealistic to draw firm conclusions about the problems and stresses experienced by families of children with disabilities. It is also difficult to ascertain whether these families are better or worse off than are comparable families without special needs children.<sup>1</sup>

One study by Jutta Joesch and Ken Smith, based on the data from over 7,000 children,<sup>2</sup> is inconclusive about chances of divorce in special needs families. It clearly states that “current knowledge about the relationship between children’s health status and their parents’ risk of divorce is limited,”<sup>3</sup> even though studies in the seventies indicated high divorce rates among parents of chronically ill children. Joesch and Smith’s data does indicate that, in the limited assortment of disabilities they studied, those “marriages with children who have congenital heart disease, cerebral palsy, or who are blind have divorce

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<sup>1</sup> Milton Seligman, “Childhood Disability and the Family,” in *Handbook of Psychosocial Characteristics of Exceptional Children*, ed. Vicki L. Schwean and Donald H. Saklofske (New York: Plenum, 1999), 116.

<sup>2</sup> These children were identified in the 1988 Child Health Supplement to the National Health Interview Survey. The survey traces the effects of 15 childhood health conditions.

<sup>3</sup> Jutta M. Joesch and Ken R. Smith, “Children’s Health and Their Mothers’ Risk of Divorce or Separation,” *Social Biology* 44, no. 3-4 (Fall-Winter 1997): 159.

rates that are 2 to 3 times higher than those with healthy children.”<sup>4</sup> However, research findings that forecast the likelihood of divorce in such circumstances are few in number.<sup>5</sup> Perhaps the difficulty in determining the functionality and health of special needs families as opposed to others relates to the complexity of the situation. Although a great number of families divorce when put under intense stress, other families get stronger. The situation has the potential to amplify the best, and the worst, in a family. Each family has the potential to learn, adjust, and transform, as well as to avoid, clash, and regress, and may experience a mixture in varying degrees of each of these. Thus, in a sense, it may not be appropriate to compare special needs and average families. As John Rolland states:

The resilience needed by a family dealing with a slowly progressing but fatal illness such as cystic fibrosis cannot be compared with that necessitated by the demands of ordinary life. Clinicians need to be careful not to append the label ‘pathological’ to families beset by serious illness since standards of normality and dysfunction appropriate to other situations do not apply to them.<sup>6</sup>

Seligman gives further insight into the reasons that comparison is inappropriate:

Families with a chronically ill child confront challenges and bear burdens unknown to other families. The shock of the initial diagnosis and the urgent and compelling need for knowledge; the exhausting nature of constant care unpredictably punctuated by crisis; the many and persistent financial concerns; the continued witnessing of a child’s pain; tensions with one’s spouse that can be aggravated by the fatiguing chronicity of care; the worries about the well-being of other children; and the multitude of questions involving the fair distribution within the family of time, money, and concern—these are challenges that parents of chronically ill children must face.<sup>7</sup>

Common sense seems to indicate that the strain for special needs families can easily exhaust their resources—material resources, physical resources, and emotional resources. This in turn seems likely to undermine the family relationally and spiritually. All too

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<sup>4</sup> Ibid., 164.

<sup>5</sup> Danielle Devine and Rex Forehand, “Cascading Toward Divorce,” *Journal of Consulting and Clinical Psychology* 64, no.2 (April 1996): 426.

<sup>6</sup> John S. Rolland, *Families, Illness, and Disability* (New York: Basic Books, 1994), 63.

<sup>7</sup> Seligman, “Childhood Disability and the Family,” 116.

often, this occurs without the family's awareness of the potential digression and pain they might face.

### Terminology

Terminology is a challenging, if not tricky, issue. In some ways it seems there is no perfect description that is free from offending peoples' feelings or convictions. One is continually in the process of wondering, "What word do I use?" hoping that the choice will not close hearts and jeopardize dialogue. Lynda Katsuno, herself in a wheelchair, states the issue well with, "labels are for jars, not for people."<sup>8</sup> In selecting terminology it seems prudent to avoid labeling the people, and instead, to specify conditions. Some of the following words are commonly heard and sometimes opposed:

Disability  
Impediment  
Handicap  
Impairment  
Exceptionality  
Differently-abled  
Physically/Mentally Challenged  
Special Needs

In the discussion of disability there are those who make statements like, "We are all disabled." The noble intention of this statement is to eliminate barriers and create a sense that we are all basically people with the same makeup. On one level, there is validity in the claim that all people are disabled, particularly if we view our present condition in comparison to what we might look like in pre-fall Eden. In the words of Brett Webb-Mitchell, "Because of our human arrogance in questioning God's commands, we live a limited, disabled, handicapped life as creatures of earthly dust."<sup>9</sup> However, on

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<sup>8</sup> Lynda Katsuno in "Going Beyond the Limits of Disability to Do and Become One World," Miriam Reidy, *WCC* 101 (December 1984): 20.

<sup>9</sup> Brett Webb-Mitchell, "The Spiritual Abuse of People with Disabilities," *Journal of Religion in Disability and Rehabilitation* 2, no.1 (1995): 59.

another level, this designation that all people are disabled is ridiculously simplistic as it glosses over the hard details for people living with profound disability, and the discrimination and difficulty that other people cannot fathom. Many will someday understand disability, on some level as almost all of humankind will eventually arrive there via accident or the process of aging. However, even these disabilities in later life cannot be compared to the child who is born never seeing or hearing or running. Those spending most of their lives able-bodied will never know the turmoil and havoc of growing up with a disability.

Although the word “disability” refers to limitation due to some impairment, there are some who disagree with the term and refute the assumption that they lack anything. Many in the deaf community take a special pride in their deaf identity, viewing themselves as a unique culture with a unique language. This very issue is the root cause of the deaf not qualifying for the federal tax considerations that the blind receive. The deaf prefer to see their inability to hear as having opened up a new world with special dimensions. They might abhor the designation of deafness as a disability, for they see themselves having special abilities that the hearing world lacks. They are thus not “disabled,” but “enabled” or “super-abled.”

The use of the term “special needs” in this paper is not meant to single people out for a negative reason. Some disdain being categorized as different. They prefer to consider themselves as just like everyone else, possessing the same needs as everyone else. Albeit everyone is special needs in some regard, and at the same time everyone has the same basic needs, so here it may be advantageous to see things as the deaf community does – with a “dignified difference.”

Difference can be an item that contributes to a positive and unique identity.

Bodily or mental difference is linked to the unique identity, capability, and spirituality of a person. This is reinforced by the term “exceptional”; however, “special needs” is used here to denote that the family with a child possessing a disability has specific needs that are generally neglected to its own detriment.

For the purposes of this study the following terminology will be utilized: I will designate the child as, “child with disability,” not “disabled child.” First, children are children, the fact that some happen to be people living with disability is of secondary importance. Outside their disabilities, these children may be very able, even super-abled, thus I will avoid the term “disabled.”

I will also avoid the term “handicap” or “handicapped,” which refers to the days when those with disabilities had little choice of employment. The predominant job options available were as street vendors, selling pencils, or worse as beggars, holding out a “handy cap” for a donation. “Handicap” will, however, be used in the sense of a “handicapping society, ” “handicapping home, ” and “handicapping church”—those places that discriminately limit people with disability.

### Demographics

Louis Harris and Associates of New York did the first sourcing on disability information in the United States. The landmark study was conducted in 1986 and was commissioned by the U.S. National Council on Disability and the International Center on Disability. The information gained was the basis for Congress crafting the Americans with Disabilities Act (ADA) in 1990. The first draft specified who would be classified as possessing disability by the federal government. At the time, the number was determined



to be 43 million people. Now there is general agreement that the number is 49 million people. Of this number, 21% possessed their disability before the age of 19. The study also showed that unemployment among those with disability was around 66%. Attitudes toward those with disability is also worth noting. Respondents who believed people with disability face some discrimination amounted to 59%, and 19% thought there was “a great deal” of discrimination. People who believed those with disability “have untapped potential to contribute” amounted to 78%, and 92% had admiration for those with disability. On a less positive side, 74% expressed pity, 58% had feelings of awkwardness, 47% of fear, and 16% of anger for what they perceived as inconvenience caused by the handicapped.<sup>10</sup>

Though the United Nations began to respond to the disability issue earlier than most countries, many policy-makers and governments have lagged behind in acknowledging the voice of people with disability. The UN designated 1981 the “International Year of Disabled Persons,” stressing the right to equal opportunity and participation. All recent world summits have also recognized people with disability as among those whose rights are being seriously violated. Despite the UN’s bringing the issue to the table, the fine words still lack the follow-up power on disability issues. An estimated 12% of the world’s population has disability; that amounts to 500 million people. Of those, 60% reside in developing countries where severe abuses are common.<sup>11</sup>

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<sup>10</sup> ICD (1986) NOD (1991) NOD/Harris (1995) surveys in National Catholic Office for Personal Disability sourced at <http://www.ncpd.org/demora.htm>.

<sup>11</sup> Rachel Hurst, “The International Politics of Disability,” *Transformation* 15, no.4 (October-December 1998): 19.

## Conditions

### Basic Rights

Not only is discrimination against those with disability prevalent, but certain fundamental rights are also commonly denied. In developed countries, most abortion laws condone aborting fetuses on the grounds of disability weeks after it is illegal for other abortions. In the United Kingdom, a pregnancy involving an unborn child with disability can be terminated right up to full term.<sup>12</sup> The following disturbing poem captures this atrocity:

“The Ones That Are Thrown Out”  
 One has flippers. This one is like a seal.  
 One has gills. This one is like a fish.  
 One has webbed hands, is like a duck.  
 One has a little tail, is like a pig.  
 One is like a frog  
 with no dome at all above the eyes.

They call them bad babies.  
 They didn't mean to be bad  
 but who does.<sup>13</sup>

Legislation in China demands the sterilization of people with disabling hereditary conditions and also forbids them to marry. In other countries, people with disability are being denied resuscitation and also more expensive treatments, such as transplants.<sup>14</sup>

### Socio-Economic Status

According to the Christian Churches Foundation for the Handicapped, people with disability have the highest rates of unemployment, poverty, homelessness, and

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<sup>12</sup> Ibid.

<sup>13</sup> Miller Williams, *Distractions*, (Baton Rouge: Louisiana State University Press), quoted in *Despite This Flesh*, Vassar Miller (Austin: University of Texas Press, 1985), 61.

<sup>14</sup> Hurst, “Politics of Disability,” 19.

suicide.<sup>15</sup> To be a child with disability in the poor third world is to be the marginalized of the marginalized. In a place where even the able-bodied roam garbage heaps for food or are sold by family members, a child who cannot contribute materially faces a heart-breaking future. A boy with Down's Syndrome in Bangladesh might be used for cruel slave labor, and a deaf girl in Thailand will likely find herself owned by someone in the sex trade. Such children can easily enter the possession of the most abusive people in their society—those shameless enough to take advantage of the most vulnerable.

### Family Stability

In her landmark book, *A Difference in the Family: Life with a Disabled Child*, Helen Featherstone speaks of the slow process that tends to pull a special needs couple apart:

These pressures operate subtly. The distance between parents grows imperceptibly as each battles fear, guilt, anger, or fatigue, as the child's disability colors how each sees the marriage...A child's disability can magnify differences that cut close to the heart.<sup>16</sup>

In the family system, each member has a particular impact upon the others. In the case where one member requires an excess or abundance of attention, there is great potential for stress on all other parts of the system. But research has been limited in this regard:

Most research on divorce and children has examined divorce as the independent variable and child functioning as the outcome variable. However, a recognition of the reciprocal nature of interaction between family members indicates the necessity of examining the extent to which children influence their parents' marriages.<sup>17</sup>

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<sup>15</sup> "Ministering With the Family Experiencing Disabilities," unpublished curriculum of Christian Church Foundation for the Handicapped. Sourced at <http://www.ccfh.org>.

<sup>16</sup> Helen Featherstone, *A Difference in the Family* (New York: Basic Books, 1980), 92.

<sup>17</sup> R. E. Emery, *Marriage, Divorce, and Children's Adjustment* (Newbury Park, California: Sage, 1988), quoted in Devine & Forehand, "Cascading Toward Divorce," 424.

The Christian Church Foundation for the Handicapped has identified other challenges that special needs families face:

- >Siblings of a child with a disability are four times more likely to be “maladjusted” than their peers who have all typical siblings.
- >Nine out of ten women who find out through amniocentesis that their unborn child has Down’s syndrome choose to abort.
- >Four out of five marriages that either produce a child with a disability, or include a spouse or child who becomes disabled through accident or disease, end in divorce.
- >The incidence of abuse in families with a disabled child is twice that of typical families.
- >Children with cognitive impairments are subject to abuse ten times more frequently than typical children.<sup>18</sup>

Domestic violence is an area of huge concern, but particularly among the disabled. Some statistics show 90-95% of women with disability are abused and or raped.<sup>19</sup> It is hard to conceive that those who already have to struggle with basic functioning may also have to face the fears and perhaps lifelong trauma of being abused, as well.

### **Theology of Disability**

#### **Discomfort With Difficulty**

In the words of Nancy Eiesland, “disability has never been religiously neutral, but shot through with theological significance.”<sup>20</sup> The way disability is perceived and integrated within the church is a direct statement about its condition. Throughout history and in the present, there are many obstacles that those with disability encounter in the church. There are likely two dominant categories of destructive verbal or non-verbal statements that say:

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<sup>18</sup> “Ministering With the Family Experiencing Disabilities,” unpublished curriculum of Christian Church Foundation for the Handicapped. Sourced at <http://www.ccfh.org/>

<sup>19</sup> Nancy Lane, “Victim Theology,” at [www.soeweb.syr.edu/thechp/spirituality.html](http://www.soeweb.syr.edu/thechp/spirituality.html), 1992.

<sup>20</sup> Nancy L. Eiesland, *The Disabled God: Toward a Liberatory Theology of Disability* (Nashville: Abingdon Press, 1994), 69, quoted in Nancy Lane, “Changing Attitudes, Creating Awareness,” at [www.soeweb.syr.edu/thechp/spirituality.html](http://www.soeweb.syr.edu/thechp/spirituality.html), 1992.

First:     Something is wrong with you:  
               You are being punished for personal or family sin.  
               You are demon possessed or demonized.  
               You are blemished and should not approach the altar.

Second: Consider your plight a blessing:  
               God is testing you and will reward you.  
               You are being purified. One day you will be a saint.  
               This is your cross—joyfully take it up.  
               Your disability is a blessing in disguise. God must think a lot of you to entrust  
               you with this.  
               God never gives us a burden that we cannot bear.

While many of these statements may be true, they are often said before the speaker has any empathetic idea of what those struggling with disability, either on a personal level or through a family member, experience. Such words only selfishly serve the speaker, and they reverberate with hollowness in the hearer's mind.

Theological answers do not come easily regarding the issue of disability, especially in the case of a newborn child. We are faced with trying to answer the question raised by the first stanza of the following poem:

#### Disability: A Lament

Creating God:  
 You made the sky,  
 clouds of purest white,  
 with rays of fuchsia and orange and magenta at sunset,  
 and faces dear with the smiles of loved ones.

Today thousands were born without sight;  
 thousands more lost vision because of injury or disease.  
 And it was evening and morning of another day.  
 Did you call this Good?<sup>21</sup>

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<sup>21</sup> Helen Betenbaugh and Marjorie Proctor-Smith, "Disabling the Lie: Prayers of Truth and Transformation," in *Human Disability and the Service of God: Reassessing Religious Practice*, ed. Nancy L. Eiesland and Don E. Saliers (Nashville, Tennessee: Abingdon, 1998), 296.

Other times the issue is avoided altogether. People find disability or suffering too uncomfortable to face and grapple with. It does not fit their limited views of a benevolent God. William Ranklin's tongue in cheek description plays with this attitude:

One, you must have nothing wrong with you; two, if you do, you must get over it immediately; three, if you can't get over it, pretend you did; four, if you can't even pretend, just don't show up, because it is too painful for the rest of us; and five, if you insist on showing up, you should at least have the decency to be ashamed.<sup>22</sup>

Eiesland observes that our theology is often skewed by a preoccupation with able-bodiedness, "Theological inquiry has frequently instituted able-bodied experience as the theological norm. The theological lenses through which we have traditionally viewed our own and others' bodies distort the physical presence not only of people with disabilities but also of the incarnate God."<sup>23</sup>

People experiencing disability, whether it be personally or through a family member, generally find themselves in a cauldron of hoping for "the cure," being prayed for by people to be cured, and yet not being cured. Others may be frustrated with the preacher who assumes that since those with disability are present in a meeting, they are looking for someone to cure them. Still others spend a lifetime looking for "the cure," and may end up missing life altogether. However, it is crucial to note that there is a difference between being cured and being healed. While "cure" deals with the alleviation of physical suffering, "healing" entails a fuller dimension. Healing may include the body, but more importantly, it refers to an inner completing and spiritual wholeness.

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<sup>22</sup> William Ranklin, *Cracking the Monolith: The Struggle for the Soul of America* (New York: Crossroad, 1994), 18, in Betenbaugh and Proctor-Smith, "Disabling the Lie," 282.

<sup>23</sup> Eiesland, "Disabled God," 99.

## Scriptures Relating to Disability

Themes related to disability are common in Scripture. These references often give insight into the issue of wholeness and the level beyond mere physical cure. The following passages are a sample of scriptures often cited with regard to disability.

### **Matthew 11:2-5**

When John heard in prison what Christ was doing, he sent his disciples to ask him, “Are you the one who was to come, or should we expect someone else?”

Jesus replied, “Go back and report to John what you hear and see: The blind receive sight, the lame walk, those who have leprosy are cured, the deaf hear, the dead are raised, and the good news is preached to the poor.”<sup>24</sup>

Although the usual focus on this portion is on the identity of Christ being the Messiah, “the one who was to come,” there is interest in the manner of Jesus’ answer to question of his identity. He mentions six different ailments which he had been actively impacting up to this point: blindness, lameness, leprosy, deafness, death, and poverty. However, Christ had also been casting out demons,<sup>25</sup> and he seems purposely to exclude the mention of “exorcism” in the list. Christ appears to be making a special distinction between these ailments and demonization. This may suggest that Christ was putting demonization in a separate category from these physical ailments. This can be taken as evidence that there is not necessarily a connection between disability and demonic activity.

### **John 9:1-3**

As he went along, he saw a man blind from birth. His disciples asked him, “Rabbi, who sinned, this man or his parents, that he was born blind?”

“Neither this man nor his parents sinned,” said Jesus. “but this happened so that the work of God might be displayed in his life.”<sup>26</sup>

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<sup>24</sup> New International Version.

<sup>25</sup> Matthew 8:16, 28-34.

<sup>26</sup> New International Version.

It is interesting to note that the miracle of healing blindness is unique to Christ. There is no instance of blindness healed in the Old Testament, and none of the disciples healed the blind. However, the issue for this discussion is the meaning of the blindness. This man was blind from birth. To bear such a curse for one's parents' sins seemed overwhelming to the disciples, who inquired about whose sin had caused this disability. But Christ turned the tables by explaining that it happened not because of anyone's sin, but rather for God's work. The disability was not a curse or consequence of evil, but a precursor to the plan of good.

This became the breakthrough realization for one pastor with disability ministering to special needs families in Mexico City, "I was the result of one sovereign, loving and creative act of God. This truth filled my heart and I began to understand that my physical handicap was permitted by God in order to make my life useful for his purposes."<sup>27</sup>

## **2 Corinthians 12:7-9**

To keep me from becoming conceited because of these surpassingly great revelations, there was given me a thorn in my flesh, a messenger of Satan, to torment me.

Three times I pleaded with the Lord to take it away from me. But he said to me, "My grace is sufficient for you, for my power is made perfect in weakness."<sup>28</sup>

The Apostle Paul, a man who healed many people, even raising others from the dead, carried in his flesh an ailment that was not to be cured. Three times he requested that the "thorn" be removed. Some commentators see this as a statement of imploring repeatedly. But God did not take it from him. This issue had the power to torment and humble the apostle. He, who wrote about crushing Satan underfoot, was subject to being

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<sup>27</sup> Raul Armando de la O. Catana, "Christ in me: a Mexican Testimony," *Transformation* 15, no.4 (October-December 1998): 7.

<sup>28</sup> New International Version.



continually taunted in his own flesh by demonic powers. Of course, God had bigger plans for Paul than a physical cure and bodily relief. For Paul realized that the “scene of human weakness is the best possible stage for the display of divine power.”<sup>29</sup>

God’s plan was to have his “grace power,” not his curing power, manifested through this situation. Grace is defined by Spiros Zodhiates as “favor done without expectation of return,” “absolute freeness of the loving-kindness of God...finding its only motive in the bounty and freeheartedness of the Giver.”<sup>30</sup> Paradoxically, this is the grace that Paul was to find amid his suffering.

This passage rejects the premise that “all illness is outside the will of God and is to be cured.” It also shows that healing may have nothing to do with faith in some situations. The issue was not faith, but God’s will. Often the unhealed are blamed for lacking faith. They not only suffer from the ailment itself, but are spiritually abused as well. Nancy Lane describes this:

Today, it is often not God’s will which is prayed for but the will of others who decide that healing will mean our disability will disappear. This becomes another form of oppression as it pushes us back into the guilt, shame and fear of stigma. This is death-making to the soul seeking a spiritual life.”<sup>31</sup>

However, we must ask, was there any occurrence where someone came to Jesus for healing who was not healed? If someone comes, it seems to infer that there is a sufficiency of faith already. The question is then divine will. Paul found the all-sufficient grace of God, and learned that when he was weak, he was truly strong.

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<sup>29</sup> C.K. Barrett, *The Second Epistle to the Corinthians* (New York: Harper and Row, 1973), 317.

<sup>30</sup> Spiros Zodhiates, *The Complete Word Study New Testament* (Chattanooga, TN: AMG Publishers, 1992), 967.

<sup>31</sup> Lane, “Victim Theology,” 2.

### Philippians 2:5-8

Your attitude should be the same as that of Christ Jesus:  
 who, being in very nature God,  
 did not consider equality with God  
 something to be grasped,  
 but made himself nothing...<sup>32</sup>

The Christ Hymn stands abruptly in the midst of the Bible as unique. In the words of F.B. Meyer, “In the whole range of Scripture this paragraph stands out in almost unapproachable and unexampled majesty.”<sup>33</sup> Peter O’Brien also confirms that there is “no convincing parallel in the whole of Greek literature.”<sup>34</sup> This creates a slight difficulty in arriving at the exact meaning. The word addressing our discussion of disability is that of *kenoo*, meaning empty or void, and translated as “nothing” or “of no reputation.” *Kenoo* is the antithesis of *pleroo*, or fullness. This word appears in Eph 1:23 as “he who *fills* all in all.” So it is amazing to consider that he, who is the fullness of all things, made himself nothing, completely emptying himself.

Though this description contradicts Gerald Hawthorne’s view that the emptying is a mere “poetic, hymnlike way of saying that Christ poured out himself, putting himself totally at the disposal of people,”<sup>35</sup> others have defined it as: “emptied himself of his glory” (Plummer), of his “prerogatives of deity” (Lightfoot), “insignia of majesty”

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<sup>32</sup> New International Version.

<sup>33</sup> F.B. Meyer, *Epistle to the Philippians* (Grand Rapids, Michigan: Baker Book House, 1952), 81.

<sup>34</sup> Peter T. O’Brien, *The Epistle to the Philippians* (Grand Rapids, Michigan: William B. Eerdmans, 1991), 217.

<sup>35</sup> Gerald F. Hawthorne, *Philippians*, vol. 43 of *Word Biblical Commentary* (Waco, Texas: Word Books, 1983), 87.

(Lightfoot, Calvin), “attributes of deity: omniscience, omnipresence, omnipotence”

(Gore, Forsyth, Mackintosh, and Meyer).<sup>36</sup>

Perhaps it is not such inaccurate rendering to say that Christ willingly handicapped himself; he volitionally entered the existence of the disabled. Amanda Shao Tan explains that, “The disability of Christ stems from the wide gap between who he is, what he has, and what he can do, in contrast to, who he became, what he forfeited, and the limitations and confinements to which he subjected himself.”<sup>37</sup> For he who created all manner of fruit and herb hungered. He who created the rivers and vast bodies of water and daily sent the dew thirsted. He who owned the cattle on a thousand hills and more was poverty stricken. He who understood all, and knew the number of hairs on every head, was misunderstood.<sup>38</sup> He who gave humankind ultimate value was devalued, a stone the builders rejected. He who was omnipresent lay constricted in a forlorn manger. He who was omniscient crawled, for he knew not how to walk. He who was omnipotent had hands and feet pinned to a tree that he himself had grown. The vast and ancient one was smooshed into time and space. Benevolent Creator abused by malevolent creature. Yes, Jesus wholly understands disability. He himself was disabled to the nth degree. He experienced the ultimate multiple-handicap. Some say this was so He would understand our pain, struggle, and agony. But is it possible that God does not understand anything? Conceivably the disabling of God was not for Christ to “understand” our plight, but rather, to be present to us.

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<sup>36</sup> Ibid., 85.

<sup>37</sup> Amanda Shao Tan, “The Disabled Christ,” *Transformation* 15, no.4 (October-December 1998): 8.

<sup>38</sup> John 7:35-36.

## Destiny of Disability

God has given both those with, and those without, disability a dignified role and calling in the eternal scope of things. This plan involves all people reaching beyond their limits and exploring the possibilities of life. Jean Vanier founded the L'Arche Federation, which forms communities for those with disability and those who are downtrodden to help serve people who were "frequently in a state of aggression or depression—with families who did not know how to cope with them." Vanier deeply believes that those with disability:

Have an important part to play in the development of the world, in helping it to find its equilibrium. They can ensure that development is not just a development of mind and matter, but a development of the total human person, who is certainly intelligence and creativity, activity and productivity, but who is also a heart, capable of love, a seeker of peace, hope, light, and trust, striving to assume the reality of suffering and of death.<sup>39</sup>

But the church has yet to awaken to this reality. In a church that is not secure and safe enough to deal with the discomforts of disability, a church that is obsessed with the issue of success, something precious will never be known – its own identity and potential. Eiesland boldly explains that, "The church (continues) to squander the considerable theological and practical energies of (people) with disabilities who...call the church to repentance and transformation."<sup>40</sup>

Those with disability have a unique role in the community. Perhaps more than anyone else they possess a capacity to represent Christ's earthly existence. In a mystical sense they are the epitome of the Christ of Philippians 2. Vinay Samuel gives insight into this special role:

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<sup>39</sup> Jean Vanier, "The Contribution of the Physically and Mentally Handicapped to Development," in *The Psychological and Social Impact of Disability*, 3<sup>rd</sup> edition, ed. Robert P. Marinelli and Arthur E. Dell Orto (New York: Springer Publishing, 1991), 3.

<sup>40</sup> Eiesland, "Disabled God," 75.



bodied forget to see. Their presence can dash a multitude of vanities, melt the most frigid heart, and cause the springs of gratitude to flow in a parched land.

### **A Handicapping Attitude**

People with disability must grow up struggling not only with their bodies, but also with the environment—an environment that may daily tell them they are insignificant. Society still exists for the able-bodied, and perhaps the biggest barriers for those with disability are “oppressive attitudes, inappropriate language, inappropriate expectations, and false stereotypes.”<sup>44</sup> Disability is therefore not primarily a medical issue but an issue of social justice. Rachel Hurst says plainly, “Disability is a rights issue, not an impairment issue.”<sup>45</sup>

But in the divine scheme, although those with disability should play a unique and vital role, they are often prevented or thwarted from fulfilling this destiny. This results in the handicapping of their humanity, and their being treated as if they are less, or even more, than people. Those with disability are often treated with pity, as charity cases—an infringement of their dignity. Or, in other situations, they may be glorified as angelic beings who are worthy of awe, yet not quite human either. Either of these treatments excludes people from full participation and communion in humanity. Such attitudes are the violation of a divine potential.

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<sup>44</sup> Chris Sugden, ed., “Biblical and Theological Reflections on Disability,” *Transformation* 15, no.4 (October-December 1998): 27.

<sup>45</sup> Hurst, “International Politics,” 18.

## CHAPTER 2 MEET THE SPECIAL NEEDS FAMILY

### **Introduction Where Are The Parents?**

A great barrier to the empowerment of special needs families might be the lack of understanding toward them. Piled high on the mountain of struggles that special needs families face is misunderstanding. Likely, at the root of this problem is the tendency for these families to be measured and evaluated by the standards of other families. This is a potent breeding ground for frustration. One such mother struggling with the disability of her nine-year-old daughter<sup>1</sup> could not resist reacting to a “nit wit PTA official’s” question regarding why she was not attending the meetings. I include her candid reaction in its entirety:

Where are the parents?

They are on the phone to doctors and hospitals and fighting with insurance companies, wading through the red tape in order that their child's medical needs can be properly addressed.

They are buried under a mountain of paperwork and medical bills, trying to make sense of a system that seems designed to confuse and intimidate all but the very savvy.

Where are the parents?

They are at home, diapering their 15 year old son, or trying to lift their 100 lb. daughter onto the toilet.

They are spending an hour at each meal to feed a child who cannot chew, or laboriously and carefully feeding their child through a g-tube.

They are administering medications, changing catheters and switching oxygen tanks.

Where are the parents?

They are sitting, bleary eyed and exhausted, in hospital emergency rooms, waiting for tests results to come back and wondering: is this the time when my child doesn't pull through?

They are sitting patiently, in hospital rooms as their child recovers from yet another surgery to lengthen hamstrings or straighten backs or repair a faulty

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<sup>1</sup> She describes her daughter as “[microencephalic], athetoid/spastic CP, Cortical Visual Impairment, Seizure disorder -- and CUTE!”

internal organ.

They are waiting in long lines in county clinics because no insurance company will touch their child.

Where are the parents?

They are sleeping in shifts because their child won't sleep more than 2 or 3 hours a night, and must constantly be watched, lest he do himself, or another member of the family, harm.

They are sitting at home with their child because family and friends are either too intimidated or too unwilling to help with child care and the state agencies that are designed to help are suffering cut backs of [their] own.

Where are the parents?

They are trying to spend time with their non-disabled children, as they try to make up for the extra time and effort that is critical to keeping their disabled child alive.

They are struggling to keep a marriage together, because adversity does not always bring you closer.

They are working 2 and sometime 3 jobs in order to keep up with the extra expenses.

And sometimes they are a single parent struggling to do it all by themselves.

Where are the parents?

They are trying to survive in a society that pays lip service to helping those in need, as long as it doesn't cost them anything.

They are trying to patch their broken dreams together so that they might have some sort of normal life for their children and their families.

They are busy, trying to survive.<sup>2</sup>

### **A Whirlpool of Emotions**

The Pearson family, like most any family, possessed hopes, dreams, and expectations. But unlike many families, Matthew and Ruth Pearson were reaching far beyond themselves, aiming for the mission field. Then, one day, life began to take a drastic turn.<sup>3</sup>

While Matthew was in seminary, David was born, nineteen months after their first son, Alex. Sudden Infant Death Syndrome almost claimed David and from there he succumbed to continuous sub-clinical seizures. Before reaching his first birthday, he was started on anti-convulsant medications. The Pearsons were told, however, that by age six

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<sup>2</sup> Sue Stuyvesant, "Where are the Parents?" at [www.ourkids.org/archives](http://www.ourkids.org/archives) 1996.

<sup>33</sup> The Pearson family is a personal friend of the author. Family names have been changed to protect the family's privacy.



David would be up to speed and in school with other kids his age. The family was faithful with physical therapy and eventually David was feeding himself, walking with support, and starting to communicate through sounds. But at age four he began to decline, and by the time he was five years old, he was like a “limp spaghetti noodle,” unable to lift his own head or even swallow. He merely lay in whatever position he was placed.

David was diagnosed with NCL (Neuronal Ceroid Lipofuscinosis), also called Batten Disease, a genetic metabolic disorder that is degenerative. Symptoms of the disease are horrific, leaving a child blind, bedridden, unable to communicate, and guaranteeing an early death. Most children die by the age of ten, but David is now nineteen. However, David only functions at the level of a 6-9 month old infant. He is fed through a stomach tube five times a day, and continues to wear diapers. When Ruth was contacted about sharing her story, she was on her back with a fractured disk, the result of lifting her teenage son.

The family also has another member. Aria is sixteen years old, and has no memory of David before his incapacitation, or of her family outside of its special needs status. Amazingly, the family lives in Asia to minister, despite the great inconveniences they face, both with regard to accessibility for wheelchairs, and the inclusion of special needs families in society.

For nineteen years now the Pearson family has struggled with the huge implications of disability within their own family. Ruth describes the impact this disability has had on the family as follows:

It's affected just about every part of our lives, both the major and the mundane: the number of children we had, choosing the city we live in, the kind of car we drive, the public transportation we take, the recreation we do, the amount of life insurance we bought, the kind of clothes and jewelry I wear, the furniture we

have, the flooring in our downstairs, where we vacation, where we attend church, the type of friends we have, how people view us, where we get seated in restaurants, the books on our bookshelves, how much and what we pack when we travel, how much laundry we do, the equipment we keep in the house (outside wheelchair, toilet/shower wheelchair, hoist lift), how often we get up during the night, the physical toll on our bodies, what we pray for. . . There is very little that is not affected by having David in our family.<sup>4</sup>

Life with a disabled child is tough. Such a life results in an intensification of many emotions. This may be seen as a process akin to Elisabeth Kübler-Ross's classic description of the stages of grief: denial, bargaining, anger, depression, and finally acceptance.<sup>5</sup> However, there are drawbacks to viewing the process in such a linear fashion. Helen Featherstone has doubts about classifying experiences solely through stage models, asserting that they "oversimplify a complex and diverse process,"<sup>6</sup> particularly in trying to define the experiences of special needs families. Rosemarie Cook states that "no model of family development, stress, and crisis, fully describes the family of a child with a disability."<sup>7</sup> Controversy regarding the number and character of stages continues to this day. Both Featherstone and Cook speak from experience; each of them has a child with disability. Featherstone, however, does discuss inevitable emotions that the family will encounter. These include fear, anger, loneliness, guilt and self-doubt.<sup>8</sup> For the purpose of this study we examine Featherstone's list and also add the emotions grief and sorrow, as research indicates the prevalence of these other emotions at work.

When disability strikes a home it is not through a well-ordered process; rather, it is through a messy process, with many digressions. The shock alone sets in motion a

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<sup>4</sup> All quotes of Pearson family from interview with author.

<sup>5</sup> Elisabeth Kübler-Ross, *On Death and Dying* (New York: Macmillan, 1969).

<sup>6</sup> Helen Featherstone, *A Difference in the Family* (New York: Basic Books, 1980), 10.

<sup>7</sup> Rosemarie S. Cook, *Counseling Families of Children with Disabilities* (Dallas: Word Publishing, 1990), 16.

<sup>8</sup> Featherstone, *Difference*, 10.

whirlpool of emotions that sends one reeling.<sup>9</sup> It is something for which no one can be prepared, and which no one can fathom. One mother of a baby with disability gives a forceful description of her disorientation in the poem “Immersion”:

Seduced by myths  
of the effortless life  
I float, footless, into adulthood,  
down streets of dreams-  
love,  
marriage,  
motherhood,  
happily ever after

Until a broken boy  
lays waste to legends.  
Dear God, the shock of it,  
the plunge, the headlong speed of it,  
the darkness,  
the fear,  
wind whistling in ears,  
and louder still  
the roar of a river,  
rising to meet my fall.

The impact rude, cold.  
The unimaginable strength of it,  
the mighty, weighty pull of it!  
I flail for bearings,  
for surface, for breath...<sup>10</sup>

### Fear

Any new special needs parent who is reasonably informed of the challenges that lie ahead will encounter fear. There will be fear that the child will face discrimination and exclusion. There will be fear of the possible effects on siblings, including bitterness and

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<sup>9</sup> These statements based on personal observation of author while participating in numerous special needs family support groups over a four year period.

<sup>10</sup> Kathleen Deyer Bolduc, “Embracing Our Brokenness: Poems and Reflections on Disability and the Kingdom,” *Journal of Religion, Disability, and Health* 4, no.4 (2001): 67.

neglect.<sup>11</sup> There will be fear of the instability of one's home, of one's faith, of one's future sanity. Fear begins to rise from the internal depths, often even before the official label has been affixed on the child. Fear may prompt parents to deny that a problem exists, as they seek to recoup themselves before they face the overwhelming truth.<sup>12</sup>

The mother of a son with multiple disabilities writes:

Fear is my unexpected companion. He comes to me in the darkest part of the night and in the brightest sunlight. He cannot be controlled, tamed. Something as minor as a cough, a twitch, unleashes Fear through my very soul. What if I miss something? What if I'm not there? What if I am there, but can do nothing?<sup>13</sup>

Over time, fear may change in quality and quantity, but it can rear its head, as illustrated above, even on a sunny day. After all, a family may feel they face a future of no relief; instead of being able to look forward to "independence, growth, and differentiation, a family may see only despair, dependence, and social isolation."<sup>14</sup>

### Anger

Anger has the potential to consume a person and family. Anger can be a substitute for hurting, and a camouflage for an assortment of other emotions.<sup>15</sup> There can be anger at families who fuss over trivial matters, anger at oneself for personal failings, and anger at society's hypocrisies and cruelties. Disability rubs raw and exposes nerves. Aria, the youngest member of the Pearson family, voices one such frustration:

My biggest pet peeve is when they [other kids] say something about being a "retard" (before they have met the rest of my family) and I feel like slapping them and saying, "What do you know? That is not retarded! You want to see retarded? I'll show you my brother!"

<sup>11</sup> Elise H. Wentworth, *Listen to Your Heart: A Message to Parents of Handicapped Children* (Boston, Mass.: Houghton Mifflin, 1974), 98-99.

<sup>12</sup> Evidenced not only from personal family experience, but in friendship with other special needs families.

<sup>13</sup> Sue, mother of a child with cerebral palsy, "Fear," (1997), at <http://www.our-kids.org/archives>.

<sup>14</sup> Milton Seligman and Rosalyn Benjamin Darling, *Ordinary Families, Special Children: A Systems Approach to Childhood Disability* (New York: Guilford Press, 1997), 88.

<sup>15</sup> *Ibid.*, 160-161.

Anger often has its source in financial strain. Insurance does not pay for everything and even a five percent deductible, when applied to a half million dollar medical bill, can clean out almost any family, leaving its members in reeling debt. They may start to tell themselves, "I've been ripped off! I deserve better!" With so many dreams dashed, one may burn with anger toward God. "After all," one reasons, "He is the sovereign cause of my pain, this supposedly loving God." But a prolonged anger toward God only increases the suffering. "By rejecting God you are truly alone, and you are afraid now in your depth of despair at the bottom of a black pit of aloneness and hopelessness. There is nothing left with which to fight, nothing for you to hold on to..."<sup>16</sup>

Mothers seem to carry most of the anger, not only because they are often the dominant caregivers, but also because they have so few escapes.<sup>17</sup> Yet fathers are not excluded from this emotion, either. In especially stressful seasons, anger that has been controlled can flare up unexpectedly. Matthew Pearson shares about the frustration of trying to manage a crisis which pushed his family even beyond the usual struggle to manage life.

When I first started doing all of David's care due to Ruth's bad back, anger was a big deal. Frustrated by my inability to control my life. Angry that I was so angry. I mean, how can you really be angry at a child whose only claim on your anger is the ability to do pretty much nothing? You can hardly claim that it's intentional. But there were times when it was all I could do to keep from shaking the kid, times when I would have to make sure Ruth, or someone, was with me watching, and even still, times when any fair referee, had they been there, would have called me for "unnecessary roughness." (Well, the Holy Spirit was there, and did make the call, actually.) The line you cross to get to child abuse gets pretty thin sometimes. People sometimes wonder how anyone could do such a thing. I have no trouble at all understanding it.

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<sup>16</sup> Elise H. Wentworth, *Listen to Your Heart: A Message to Parents of Handicapped Children* (Boston: Houghton Mifflin, 1974), 124.

<sup>17</sup> Hillary Schofield, ed., *Family Caregivers: Disability, Illness, and Aging* (St. Leonards, N.S.W.: Allen and Unwin, VicHealth, 1998), 78.

## Loneliness

Another emotion voiced by many with disability is loneliness. People with disability are generally noticeably different than the able-bodied, this difference can create walls that isolate those with disability from inclusion. The following lines convey this solitude.

I'm handicapped and wheelchair bound  
 Expected to sit and not make a sound  
 Just to smile and let the World go by  
 With Saintly patience and never sigh.

Inside my head thoughts come and go  
 Ideas are born which long to flow  
 Flow from my lips and link me with others  
 But my words sound strange so no one bothers.<sup>18</sup>

A child with disability may never, in a lifetime, meet another child with the same challenge. For a child, this being different, this never “fitting,” can be a lonely trail to trek. The child has a fundamental difference, even from his/her own family, and in some cases may be emotionally or socially severed from his/her family. One sad example of this is found in the entire generation of deaf children whose parents were advised not to use sign language for fear that it would inhibit their children’s development of speech. However, most deaf children never learn to read lips. The tragic result has been an inability for parent and child to adequately communicate with each other. Deafness isolates in many ways, as Mary Elford describes in “What is Deafness?” “It is pain. It is

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<sup>18</sup> Anonymous, “The Outsider,” sourced at <http://www.our-kids.org/archives>.

frustration when someone refuses to repeat something for you. It is withdrawing into silence, pretending that it doesn't matter that conversation is flowing over you."<sup>19</sup>

This description seems akin to the loneliness in other disabilities, as well. There is pain and there is withdrawal. Life becomes too painful when family members associate with people who say stupid and hurtful things, as Aria explains, "I suppose the most difficult thing is how other people react to us as a family when David is around. Everyone knows us, 'Oh, you are the one with the, the...brother.' My response, 'Yeah, I have two. (BIG DEAL).'" Siblings abhor being known as the one with the "weird" family member, as though they were part of the Adams Family with a "Thing," or "Cousin It." Family members may feel unable to share their lives with others for fear of being wounded. Consider the hurt of Rosalyn, a mother who poured out her anxieties about her little girl to a friend; the friend urged her to quiet down and then dropped the bomb: "These children don't generally live very long anyway." Rosalyn froze, unable to speak. She later wrote, "I never poured out my heart to anyone again."<sup>20</sup> Even doctors have been known to blunder with phrases like, "Don't get too attached to this child or it will break your heart."<sup>21</sup>

There are two paths to isolation. On the first path, the family may be cut off by others who cannot bear to endure the pain or inconvenience of unpleasant sounds, smells, and situations. On the second path, the weary and smarting family may, of necessity, drift away themselves. Special needs families struggle with limited resources and lack the energy necessary to weather hurtful comments.

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<sup>19</sup> Mary Elford, "Part of Who I Am," in *Not All Violins: Spiritual Resources by Women with Disabilities and Chronic Illnesses*, ed. Charlotte Caron (Toronto: United Church Publishing, 1997), 39.

<sup>20</sup> Featherstone, "Difference," 58.

<sup>21</sup> Dick Sobsey, letter to Joan, "Coping with Loss of Support and Hurtful Comments," at <http://www.our-kids.org>, 1995.

## Guilt and Self Doubt

Who is ultimately responsible for a child's disability? Physicians, in-laws, and even spouses may inadvertently, or even blatantly, speak in a way that assigns blame, and blame can be a gargantuan burden to carry. In the case where the disability is caused by some failure, the person responsible has the continual reminder, day after day, of his/her guilt; the child becomes a symbol of the guilt. Continuous and unaddressed blame in a family may continue to work its poison, working deeper and deeper to disintegrate the family.<sup>22</sup>

But blame is not usually limited to one family member. Each member can carry a measure of guilty feeling. Children with disability may feel guilty about the struggle their disability brings to the family, and they will likely blame themselves in the event of a divorce. Siblings might feel guilty for thinking about how the death of a disabled brother or sister might better their lives and the life of the family. Parents can feel guilty for wishing malady upon a friend's child, so as to have a friend with whom they could share their heartache. Family members may secretly hope for the misfortune of others, toying with thoughts that are actually abhorrent to them, and then feel guilty for having stooped so low. Then there are always the "lesser guilts" of neglecting other family members, social functions, extended family needs, and church duties, that pile guilt on top of guilt. Matthew Pearson explains his struggle in trying to care for his son and his own life adequately:

Guilt is a big one. All the billion things you could have done and didn't, are always lining up leering at you at the end of the day. Sometimes you have the presence of mind to remember who you are, and tell them to get lost. You're not

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<sup>22</sup> Elise H. Wentworth, *Listen to Your Heart: A Message to Parents of Handicapped Children* (Boston, Mass.: Houghton Mifflin, 1974), 43.



God, after all, and have to choose from a finite, time-bound list of possibilities that you are going to do. Sometimes you just get depressed.

### Grief and Sorrow

Similar to the death of someone dear, there is a lingering sorrow even after many years have passed, but for those affected by disability, it is the uncertain sorrow of many undefined and precious things lost. Something seems morally wrong with babies and small children having to suffer, and experiencing this situation firsthand can be an agonizing grief itself. Likely, this grief and sorrow never completely subsides, but is revived repeatedly during different life situations and life stages. Sorrow is revived when the parent of an autistic boy sees another child smile and make a friend. It is revived when the mother of a deaf girl hears another little girl sing a song or play the piano. It is revived when the father of a wheelchair-bound boy watches another boy score a touchdown.<sup>23</sup>

A mother named Rhonda speaks of her son, Tom, who is affected by spina bifida:

Seeing other normal healthy babies sometimes hurt. I remember crying for hours after a family get-together when Tom was three. I watched him clapping and celebrating along with everyone else as his one-year old cousin took her first steps. Tom should have been running and jumping and playing with other children. It broke my heart to see him so incapacitated, yet he was happy for her.”<sup>24</sup>

Another great source of sorrow is found in the misunderstanding and hurtful words that seem to bump the scabs off of healing wounds. Ruth, of the Pearson family, explains that the most difficult issue is:

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<sup>23</sup> The essence of this dynamic has been distilled through the author experiencing the testimony of many other special needs families.

<sup>24</sup> Delores Kuenning, *Helping People Through Grief* (Minneapolis, Minnesota: Bethany House, 1987), 33.

How other people respond (or don't respond)...The people who I thought would be most supportive and helpful have been the most hurtful. Often it's been the non-Christian who has been the most helpful (no pat answers and no preaching). One of our closest friends talked to me of how it's too bad Daniel won't be in heaven as he "Can't confess with his mouth, Jesus as Lord, which the Bible clearly states is necessary for salvation."

Grief can easily grow into chronic sorrow, as well. The mixture of sorrow and fatigue can brew depression into a swampy, colorless, gray world where nothing seems to bring enjoyment. Even small things become unbearable, and a trip to the grocery store exhausts what little energy has been mustered up for the day.

### At Wits End

What happens when the whirlpool of emotions sucks one into its depths? On the negative side, there are many horrible stories. There are stories of desertion, where a spouse gives in to fantasies about falling in love with someone else and starting a whole new life in another place. There are stories of abuse, where helpless children are stuffed away in dark closets for years. There are stories of murder and suicide, where parents strangle or knife children, and then destroy themselves, as well. They are all hellish stories of unimaginable horror, yet they do happen.

The horrible, climactic events of special needs family members who have gone over the edge get most of the publicity. There are, however, many unpublicized stories of silent suffering and isolation where people have come to the end of their rope, then dangled there for years. Where people have exhausted all their resources and still hang on, continuing to face the onslaught:

I prayed. Over and over, I prayed, "God, please give me the grace to withstand this." And my other prayer, long night after long night, was "God, I know you never give a person a greater burden than they can bear. Your math is wrong here: I've had all I can take. I've searched the deepest pockets of my soul, and

then of my entire being, and I've found wellspring after wellspring that I never knew was there. But now I'm all out. It's time for a break. Are you listening?"<sup>25</sup>

Despite the struggle, some families find the means to move ahead, even if for just one more day, and find firm enough ground to get footing for just one more step. Ruth, of the Pearson family, speaks about this experience, "There are instances where we were totally thrown on God's mercy, and we have seen God provide exactly what we needed at the perfect time. In other instances God has given grace to get through hellish days sane, and that in itself is a miracle."

In a world saturated with broken lives and broken homes, there is a longing to hear stories of hope. Each person clings to the hope that in the end, all injustice will be righted and all suffering will have been meaningful. Such a hope is captured in the lines of:

"Grace Alone"

Terrorized in the face  
of her son's Furies  
she calls on a God  
whose name is Love  
before slipping into sleep  
muddled with truth  
too awful to bear

While drops of pain  
which cannot forget  
build night by night  
moon by moon  
upon her heart  
until, in her despair  
against her will  
comes wisdom  
through the awful grace  
of God<sup>26</sup>

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<sup>25</sup> Helen Betenbaugh, "Disability: A Lived Theology," *Theology Today* 57, no.2 (July 2000): 206.

<sup>26</sup> Kathleen Deyer Bolduc, "Embracing Our Brokenness: Poems and Reflections on Disability and the Kingdom," *Journal of Religion, Disability, and Health* 4, no.4 (2001): 72.

### Understanding Family Cohesion and Control

In beginning to understand a family system, it is helpful to engage a model for evaluating its health. Numerous tools are available to help place a family on some scale of vitality and functionality. There is, however, a danger in giving a family a label or finding some psychopathological definition of a family that can lock its members into a pattern of behavior. One useful tool for evaluation is Robert Beaver's Systems Model, which consists of five developmental levels any given family can fit into.<sup>27</sup> Family functioning is rated from 1, the highest, to 5, the lowest. The most densely populated cluster, consisting of 60 percent of families, tends to occur midrange, at Level 3.

A Level 5 family is termed the "family in pain" and is considered... severely disturbed. In this type of family, nobody seems to have authority and leadership is absent. If someone tries to rise up and initiate an idea, he/she is likely to be automatically negated by the others. These families are haunted by the ghosts of many unresolved past hurts. They also cannot face any potential losses the future might hold. Developmentally, this family never progresses but continues in its perpetuation of a lose-lose scenario. Though this family desperately longs for cohesion, or intimacy, it continually fails at fostering it.

A Level 4 family is a "polarized family," and is also considered a "borderline" family. In this family, there is a desperate effort to conquer disorder and bring control. This is a pendulum swing from the Level 5 family. Here, family members see everything in black and white, and each action is considered either wonderful or atrocious. Though it is hard to believe, this family is an improvement over the Level 5 family. It can be

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<sup>27</sup> Maggie Scarf, *Intimate Worlds: Life Inside the Family* (New York: Random House, 1995), 24-29.

compared to a nation that has a tyrannical autocrat who institutes boundaries and laws, as opposed to a nation without any government or justice system whatsoever. In this family, one member works to control what everyone thinks and does, and though this is effective for the short term, it will eventually fail. Level 4 families solve the problem of cohesion, but the emotional price is great: there is resentment and spirits are crushed.

The Level 3 family is the “rule bound family,” the family classified as midrange. In such families, the influence of family members’ close relationships are the source of order. Each member of this level of family lives by the underlying premise that “if you love me then you will do what you know I like.” However, rules are still more important than people. In this legalistic style of relating, family members can become resentful of the constant sense of guilt they carry. In the words of Robert Beavers, an “invisible referee” is always keeping watch. Family members feel basically un-trusted and obligated to do things because they “ought” to, not because they would like to. Unfortunately, besides being a depressing environment, the Level 3 family does not allow people to get in touch with themselves, and worse, it can keep family members from ever finding true intimacy.

Level 2 is the “adequate family” and Level 1 is the “optimal family.”

Characteristics of both are similar, and an increase in the quality of these characteristics differentiates Level 1 from Level 2. These families are able to deal comfortably with both loving feelings and feelings of frustration with each other. They can deal flexibly with change and keep a clear sense of direction. There is a deep sense of dependability and

trust among family members and a secure feeling that no matter what happens, “we can work it out.”<sup>28</sup>

One can now begin to imagine the varied impact that disability will have on different family types. The Pearson family has matured through many difficult years to become a family that can express love and frustration, and can be flexible while maintaining direction. This places it in the vicinity of a Level 1 family. Unfortunately, the nineteen years experience of the Pearson family’s special need status is a long time to evaluate. What the family looked like when the crisis initially occurred is unknown. Of course, some families are better prepared than others. Certain families are struggling already with poor cohesion and control mechanisms. These poorly prepared families may be tragic examples of the metaphorical “sitting duck.”

### **Understanding Stress and Coping**

Another relevant measurement for the special needs family is its ability to cope with stress. Family functioning is often described in terms of the relationship between stress and adaptation.<sup>29</sup> The degree of stress experienced by a family has much less to do with an event than with the factors that define the family’s stress hardiness, such as child/parent interactions, family resources, and coping strategies. The same event can be for one family as mild as a bat flying around the house, but for another family, as severe as a holocaust, depending on each family’s coping abilities. Which families will succeed

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<sup>28</sup> Scarf, *Intimate Worlds*, abbreviation of Beaver’s System, 24-33.

<sup>29</sup> P. Minnes, “Family Stress Associated With a Developmentally Handicapped Child,” *International Review of Research in Mental Retardation* 15 (1988):195-224, in “Effects of Stressors, Internal Resources, and Coping Strategies on the Adaptation of Families of Children With a Mental Handicap,” Doris Paez, (Ph.D. diss., University of Florida, 1992), 2.

depends on whether their vulnerabilities will be counter-balanced by their coping strengths.<sup>30</sup>

Empowering families is about identifying strengths and building upon those qualities. A study by D. Abbott and W. Meredith indicates that adjustment to stress is strongly related to several factors: each family member's self view, the strength of the marital relationship, and the family's ability to reframe stressors in positive ways.<sup>31</sup> Later chapters will discuss means to help a families build upon the strengths of self-view and reframing of stressors.

Models predicting stress adjustment are useful in understanding the effect of stress on families. The most prominent model, the ABC-X, was devised by Reuben Hill in 1949. Today, most models are some variant of Hill's approach. The majority of empirical support for this model comes from studies involving families with children who have severe illnesses or disabilities.<sup>32</sup> In 1989, Gallagher and Bristol suggested this model as an accurate representation of what occurs within special needs families.<sup>33</sup> In this model, the "A" represents the characteristics of the stressor event, the "B" represents the family's internal resources, and the "C" stands for represents the family's definition of the event. The interaction of these three factors then contributes to the preventing or precipitation of "X", which is the crisis.

The Severity of the stressor, or disability, usually increases the stress on a family to the point of crisis. Stress was originally described by Selye in 1956 as a "noxious

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<sup>30</sup> Pauline Boss, "Family Stress," in *Handbook of Marriage and the Family*, ed. M. B. Sussman and S. K. Steinmetz (New York: Plenum Press, 1988), 695.

<sup>31</sup> D. Abbott and W. Meredith, "Strengths of Parents With Retarded Children," *Family Relations* 35 (1986): 371-375, in Paez, "Coping Strategies," 4-5.

<sup>32</sup> Paez, "Coping Strategies," 26.

<sup>33</sup> *Ibid.*, 6.

stimulus.”<sup>34</sup> By 1974, it had been redefined and interpreted more neutrally, leading Lazarus to term it a mere “threat.”<sup>35</sup> Central to the occurrence of stress is a change or a stimulus that threatens the present equilibrium. In this disruption of the equilibrium, the system is pushed off balance and strained. Crisis, on the other hand, is change that is so severe that the system is immobilized and incapacitated. Crisis is acute dis-equilibrium as opposed to stress that has merely disturbed the equilibrium.<sup>36</sup>

The severity of a disability often has a strange inverse effect on a family, which may actually decrease its severity on the system. The likely cause is that with severe disability, a family tends to face the difficulty straight on; unrealistic expectations are reduced, denial is impossible, and a family is pushed to make the needed adjustments immediately.<sup>37</sup>

One hugely significant element related to the severity of disability is the status of the disability itself. Is the child educable or trainable? Is the disability something that may improve, as is the case of a child with hearing loss who may benefit from the use of a cochlear implant for communicating, or a child with incapacities who may learn to walk with the use of a prosthesis? Will the situation continue to increase in severity, as is the case with a child whose cerebral palsy may progressively worsen, or one whose cystic fibrosis will end the young life prematurely?

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<sup>34</sup> Boss, “Family Stress,” 698.

<sup>35</sup> Ibid.

<sup>36</sup> Ibid., 700.

<sup>37</sup> M. Bristol, “Family Resources and Successful Adaptation to Autistic Children,” in *The Effects of Autism on the Family*, ed. E. Schopler and G. Mesibov (New York: Plenum, 1984), 289-309, in Paez, “Coping Strategies,” 30.



The following classic diagram traces the progression from stressor to outcome:

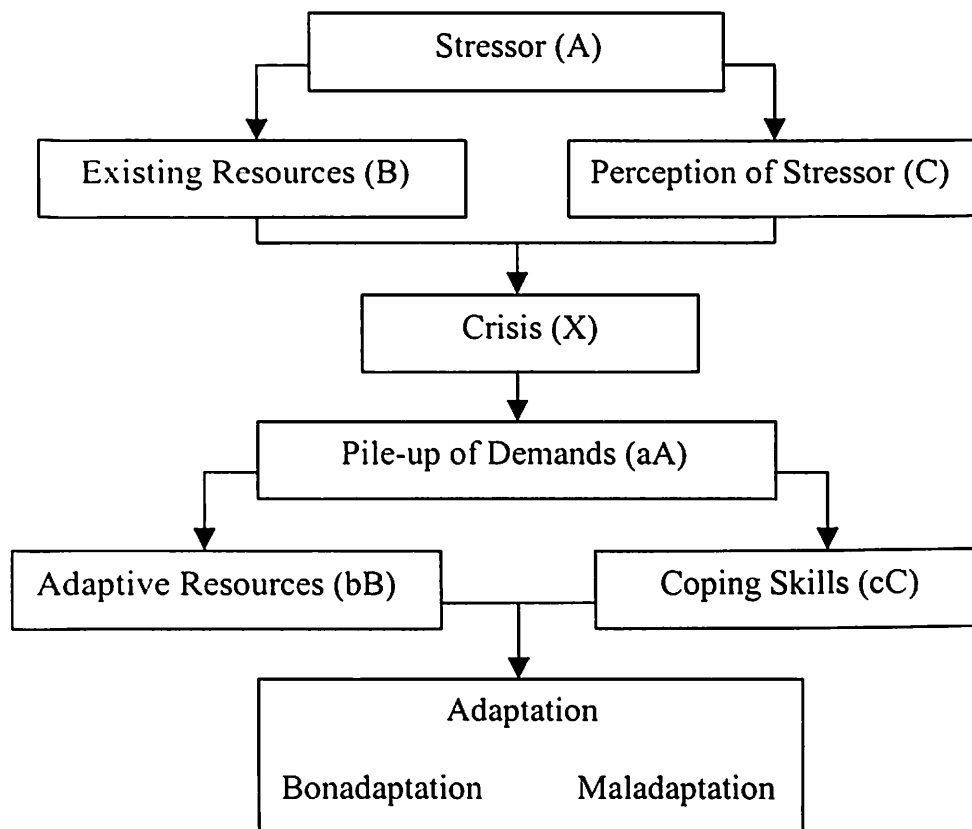


Figure 2.1. The Double ABC-X Model (McCubbin & Patterson).<sup>38</sup>

The Double ABC-X model builds off of Hill's classic rendering of the factors relating to stress and crisis. However, it also makes some additions to the equation: the pile-up of demands, the adaptive resources, and the coping skills. Another model that gives insight into the dynamics of dealing with stress is the Five-Factor Model. The Five-Factor Model is comprised of Hill's stressor event, family resources, and definition of the event, and two additional factors: family residual past and family readiness. Residual past refers to the family's past problem solving experience, unresolved conflicts, and leftover

<sup>38</sup> H. McCubbin and J. Patterson, "The Family Stress Process: The Double ABCX Model of Adjustment and Adaptation," in *Advances and Developments in Family Stress Theory and Research*, ed. H. McCubbin, M. Sussman, and J. Patterson (New York: Haworth, 1983), 21-35, in Paez, "Coping Strategies," 25.

compromises. Readiness has to do with the issues of preparedness and predictability for crisis.<sup>39</sup>

It is also beneficial to gain more insight into coping strategies. Coping strategies are cognitions or behaviors aimed at decreasing the impact of stressors. Of course, there are both helpful and unhelpful types of coping strategies which Ann Bailey and Stephen Smith describe as either “adaptive,” which is actional and involves changing the self or source of stress, or “palliative,” which is emotional and involves engaging in activities such as avoidance, denial, blame, and wishful thinking.<sup>40</sup> Coping strategies can also be seen as either external or internal.<sup>41</sup> External strategies may be social, as in support groups, or spiritual, as in church help. Internal strategies may also be spiritual, as in one’s reliance on God, or mental, as in reframing the situation to see it differently.

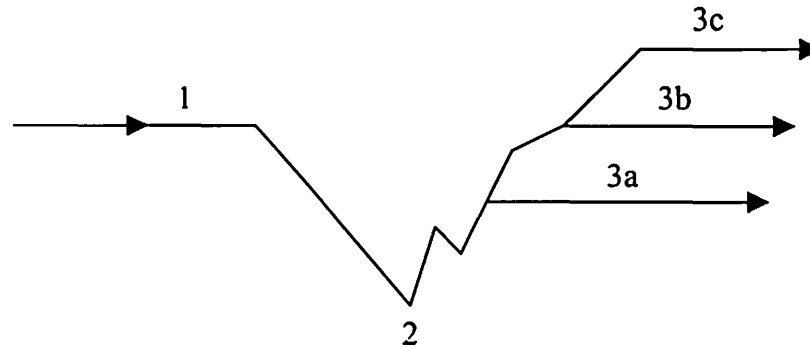
The following diagram shows the potential outcome of crisis events. There are three possible results: worse off, back to normal, and better off.

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<sup>39</sup> Cook, *Counseling Families*, 21.

<sup>40</sup> Ann Bingham Bailey and Stephen W. Smith, “Providing Effective Coping Strategies and Supports for Families with Children with Disabilities,” *Intervention in School & Clinic* 35, no. 5 (May 2000): 294.

<sup>41</sup> R. Fewell, “The Measurement of Family Functioning,” in *Evaluating Early Intervention Programs for Severely Handicapped Children and Their Families*, ed. L. Bickman and D. L. Weatherford (Austin, Texas: Pro-Ed, 1986), in Paez, “Coping Strategies,” 46.



- 1= Level of family functioning before event
- 2= Low point in disorganization
- 3= Level of reorganization
  - a. below previous level of functioning
  - b. equal to previous level of functioning
  - c. higher than previous level of functioning

Figure 2.2. Diagram of family crisis model.<sup>42</sup>

In considering the stress and crisis experienced by the Pearson family, one marvels at how well they have coped. One may hypothesize that the history of Matthew Pearson's family of origin has contributed significantly to the family's success. Matthew's parents ministered in the deaf community; thus Matthew and his family of origin lived intimately in a culture of disability. This history has likely had a powerful influence on factors within the Five-Factor Model, such as family resources, definition of event, family residual past, and family readiness. Not only Matthew, but even his family of origin were partially prepared for the birth of a family member with disability. Because of this family history, David's paternal relatives would be able to define the event more readily and positively. Much of their social life had already involved people with disability, and spiritually, they had likely already dealt with some of the crucial

<sup>42</sup> R. Hill, *Families Under Stress* (New York: Harper & Row, 1949) and E. L. Koos, *Families in Trouble* (New York: King's Crown Press, 1946) in Boss, "Family Stress," 697.

questions that challenge faith. They had a rare advantage over the average family facing an occurrence of disability.

### Positive Outcomes Despite Crisis

Without a doubt, most literature and studies focus on the dangers and problems associated with having a child with disability. However, all is not negative. Many families seem to thrive on the challenge,<sup>43</sup> some marriages are strengthened,<sup>44</sup> and some families grow in cohesiveness and adaptability.<sup>45</sup> When families are undergoing stress, there seems to be an intensification of strength, as well as an intensification of strength weakness. Both the best and the worst will be magnified in the situation of life with a child who has disability.

Though empirical studies that document the positive sides are few, much evidence for the positive contribution of having a child with disability comes from the narratives of parents themselves. Murray gave testimony to this as far back as 1959:

It has been my privilege to have talked with hundreds of parents of retarded children. One of the favorite themes which permeates our conversation is how much our children have meant to us. This thought runs like a bright golden thread through the dark tapestry of our sorrow. We learn so much from our children...in patience, in humility, in gratitude for other blessings we had accepted before was a matter of course; so much in tolerance; so much in faith—believing and trusting where we cannot see; so much in compassion for our fellow man; and yes, even so much in wisdom about the eternal values of life.<sup>46</sup>

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<sup>43</sup> H. I. McCubbin, M. B. Sussman, and J. M. Patterson, *Social Stress and the Family* (New York: Howarth Press, 1983), in *Support for Caregiving Families: Enabling Positive Adaptation to Disability*, ed. George H. S. Singer, and Larry K. Irvin (Baltimore: Paul H. Brookes Publishing, 1989), 12.

<sup>44</sup> Kazak & Marvin in Singer, "Support for Caregiving Families," 12.

<sup>45</sup> H.L. McCubbin, in Singer, "Support for Caregiving Families," 12.

<sup>46</sup> M. A. Murray, "Needs of Parents of Mentally Retarded Children," *American Journal of Mental Deficiency* 63 (1959): 1087-1088, in "Positive Adaptation and Coping Strengths of Families Who Have Children with Disabilities," Jean Ann Summers, Shirley K. Behr, and Ann P. Turnbull, in Singer, "Support for Caregiving Families," 28.

Mullins evaluated 60 books written by parents of children with disabilities, and distilled the common principles contained in all the writings. The result was four prevalent themes:

A realistic appraisal of the disability  
 Extraordinary demands on the family  
 Extraordinary emotional stress  
 Resolution and growth<sup>47</sup>

In spite of all the extraordinary demands and stresses, the majority of writers felt their lives had been enriched and made more meaningful. Many families vouch for the fact that they have entered into life on a different level, and it is something that they would not trade or have otherwise.

Alex Pearson shares about his “baby brother”:

Although it is a world that is full of pain and sorrow, one of David’s smiles brings infinitely more joy. It is not really that the smile erases the pain, but it somehow makes the pain bearable. I can’t really explain it except to say that my brother’s smile is so beautiful that it makes you forget about the pain, the way looking at a rose makes you forget about its thorns.

Alex, now a student at UC Berkeley, seeks to function in a world of skewed values, but is reminded, by David, of what really matters:

The most important lessons I have learned through him (David) are about perspective. Another vivid memory is before going up to study after coming home from high school, I tousled his hair for half a second longer than normal when I said “Hi” to him. He looked up at me and I was looking down at him, and I held his gaze instead of going off to do homework, and he started laughing and laughing and laughing. And I thought, “Why do I spend so much time studying for Advanced Placement tests when with 5 seconds I can bring this much happiness?”

Turnbull and her associates identified a list of benefits, experienced by many special needs families, that is quite impressive:

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<sup>47</sup> J. B. Mullins, “Authentic Voices From Parents of Exceptional Children,” *Family Relations* 36 (1987): 30-33, in Summers, Behr, and Turnbull, “Positive Adaptation,” 28.

Increased happiness  
 Strengthened family ties  
 Expanded social network  
 Greater knowledge about disabilities  
 Learning tolerance and sensitivity  
 Expanding career development  
 Assuming personal control

Greater love  
 Strengthened religious faith  
 Greater pride and accomplishment  
 Learning not to take things for granted  
 Learning to be patient  
 Increased personal growth  
 Living life more slowly<sup>48</sup>

The familiar prayer of an unknown Confederate soldier may partially explain what these families are experiencing.

#### A Prayer

I asked God for strength that I might achieve,  
 I was made weak, that I might learn humbly to obey.  
 I asked for health, that I might do greater things,  
 I was given infirmity that I might do better things.  
 I asked for riches, that I might be happy,  
 I was given poverty, that I might be wise.  
 I asked for power, that I might have the praise of men,  
 I was given weakness, that I might feel the need of God.  
 I asked for all things, that I might enjoy life,  
 I was given life, that I might enjoy all things.  
 I got nothing I asked for—  
 but everything I had hoped for.  
 Almost despite myself,  
 my unspoken prayers were answered.<sup>49</sup>

<sup>48</sup> A. P. Turnbull, S. K. Behr, and N. Tollefson, "Positive Contributions That People With Mental Retardation Make to Their Families" (Paper delivered at the Association on Mental Deficiency, Denver, CO, May 1986), in Summers, Behr, and Turnbull, "Positive Adaptation," 29.

<sup>49</sup> M. Cleland, *Strong at the Broken Places*, in "Life's Challenges: Curse or Opportunity? Counseling Families of Persons With Disabilities," Mary R. Hulnick and H. Ronald Hulnick, in *The Psychological and Social Impact of Disability*, 3<sup>rd</sup> edition, ed. Robert P. Marinelli and Arthur E. Dell Orto (New York: Springer Publishing, 1991), 267.

CHAPTER 3  
COLLABORATING WITH THE SPIRIT:  
THE APPROACH OF SPIRITUAL DIRECTION

**Introduction**  
**Description of Spiritual Direction**

The term “spiritual direction” has often induced feelings of animosity, as it seems to infer the authoritarian control that many have experienced in spiritually abusive environments. The mere mention of this term easily calls to memory spiritually oppressive leaders and systems that have brutalized the vulnerable. Without a doubt, some of the greatest spiritual abuses occur when a mortal aims to usurp the influence of God in another’s life. This term is akin to a statement made by Boniface VIII. In 1301 he wrote these words to the king of France: “Hearken, dearest son, to the precepts of thy father and bend the ear of thy heart to the teaching of the master who, here on earth, stands in place of Him who alone is master and lord.”<sup>1</sup> Such a demeaning attitude does not have any place in true spiritual direction. One revealing definition of spiritual direction is that it is “nothing more than a way of leading us to see and obey our real Director—the Holy Spirit, hidden in the depths of our soul.”<sup>2</sup> This is precisely what true spiritual empowerment is about—helping others help themselves be helped by God, that they might be emancipated pilgrims instead of emaciated patients.

Occasionally, spiritual direction is likened to discipleship. However, while both fulfill important roles, the focus of each is principally different. While discipleship focuses on knowing and doing the will of God, following in his footsteps, so to speak,

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<sup>1</sup> John Mundy, *Europe in the High Middle Ages* (London, 1973), 323, in “Christian Adulthood,” William J. Bouwsma, in *Adulthood*, ed. Erik Erikson (New York: W.W. Norton & Co., 1978), 84.

<sup>2</sup> Francis Kelly Nemeck and Marie Theresa Coombs, *The Way of Spiritual Direction* (Collegeville, Minn.: Liturgical Press, 1985), 84.

spiritual direction focuses on how one can be more present to and with God.<sup>3</sup> Thus, while discipleship generally emphasizes character and service, direction concentrates on sensitivity to God and entering into His life.

Central to the practice of true spiritual direction is the belief that the director does not actually give direction, but is involved in discerning the Direction that already exists within the directee. Thus the director, with a small “d”, must be careful to follow the Director—speaking only what, how much, and when, he is led. It is in this setting that the director can help the individual “bring out his inner spiritual freedom, his inmost truth, which is what we call the likeness of Christ in his soul.”<sup>4</sup> What makes direction different from most counseling is the surrender of human control. For “the agenda of spiritual direction is to have no agenda except to be open to God.”<sup>5</sup>

Specifically detailing the characteristics of spiritual direction can be challenging. Each director has a special gift and slant, and thus the direction of each is unique, though graced by the same Spirit. Joel Giallanza observes that “principles for spiritual direction can be as many and varied as there are writers and speakers and directors to present them. Most directors however, would likely agree that each directee is moving toward union with the Lord in a unique way.”<sup>6</sup>

### **History: Pre-Modern Roots**

The tradition of spiritual direction has its roots in the monastic setting of the Desert Fathers and Mothers who lived as hermits, or in cloisters, in the wastelands of Palestine, Egypt, and Samaria. These ascetics sought a lifestyle that made a statement against the societies from which they had withdrawn. However, despite their distance,

<sup>3</sup> John R. Throop, “Becoming a Spiritual Director,” *The Clergy Journal* 76, no.8 (July 2000), 6.

<sup>4</sup> Thomas Merton, *Spiritual Direction and Meditation* (Collegeville, Minn.: Liturgical Press, n.d.), 16.

<sup>5</sup> Carol Stream, “Making Space for God,” *Christianity Today Magazine*, 23 April 2001, 89.

<sup>6</sup> Joel Giallanza, “Integration in Spiritual Direction,” *Contemplative Review* 13, no. 4 (Winter 1980): 31.



they made ample contact with souls still living in those societies. People seeking a deeper encounter with God would make the painstaking journey to visit these desert sages and receive spiritual guidance.<sup>7</sup> The emphasis of the guidance was spiritual, the words they spoke were not intended to be profound, but rather, they were intended to be Spirit sourced. Two outstanding guides during this period were Evagrius and Cassian.<sup>8</sup>

Over the years, spiritual direction developed and became more refined. The Orthodox tradition has continued to have a strong heritage of direction. The director is referred to as a “staretz” or father, and the emphasis has been to truly see face and accurately hear voice.<sup>9</sup> St. Seraphim of Sarov has been considered perhaps the greatest staretz of all time. Some special aspects which Orthodoxy added to the role of the director include: (1) insight and discernment to see into the heart, (2) to love and make sufferings his own, and in this way share in the passion of Christ, (3) power to transform the cosmos by intensity of love.<sup>10</sup>

The Catholic tradition of direction is also exceptionally rich. Catholicism has encouraged the development of direction in both the mystical and the practical. Bernard said of his director, the monk Humbert, “He knew so well how to penetrate into the corners of a sick conscience that he who went to confess to him might have believed that he had seen everything, been present at everything.”<sup>11</sup> Eventually, Ignatius developed an

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<sup>7</sup> *Streams of Living Water: Celebrating the Great Traditions of the Christian Faith*, Richard Foster (San Francisco: Harper, 1998), 32. In *The Life of Antony*, Athanasius summarizes how this desert father ministered to visitors suffering a great variety of ailments.

<sup>8</sup> Kenneth Leech, *Soul Friend: The Practice of Spiritual Direction* (San Francisco: Harper & Row, 1980), 42. Leech gives one of the best brief overviews of the history of direction.

<sup>9</sup> *Ibid.*, 46-47.

<sup>10</sup> *Ibid.*, 49.

<sup>11</sup> *Ibid.*, 53.

entire school of systematic spiritual direction. The Ignatian retreat brought together many exercises into a practical training method of spiritual development.<sup>12</sup>

Besides Ignatius, perhaps the two most dominant figures referred to in Catholic spiritual direction are St. John of the Cross and is St. Teresa of Avila, both of whose writings have been used extensively in direction. Though St. John wrote only a couple dozen poems, and the accompanying commentary, he gave profound insight into the stages of progress toward union, with particular emphasis upon the “dark night of the soul” and the “dark night of the spirit.”<sup>13</sup> St. Teresa, a contemporary and friend of St. John, though older, exhibited immense humility, and in a way came under St. John’s direction. Her work, *Interior Castle*, is a classic of spirituality, tracing the levels of entry into the unified life.<sup>14</sup>

The Catholic tradition produced many greats of spiritual direction, from Francis De Sales, Jean Paul De Caussade, and Jean N. Grou, to more recent figures like Benedictine Dom Columba Marmion and Joseph de Guibert.<sup>15</sup> Other noteworthy figures inhabit other Christian traditions. Reginald Somerset was from the Anglican Church. Martin Bucer, who authored *On the True Cure of Souls*, was a Lutheran. Renowned Quaker, George Fox, was well known for spiritual guidance. Others in the Protestant tradition who incorporated of confession and guidance characteristic of spiritual direction include Max Thurian, Deitrich Bonhoeffer, and Neville Ward.<sup>16</sup> Many elements of

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<sup>12</sup> Ignatius Loyola, *The Spiritual Exercises of Saint Ignatius*, trans. Pierre Wolff (Liguori, Mo.: Triumph, 1997). This classic is the manual for the systematic and intensely practical Ignatian retreat.

<sup>13</sup> John of the Cross, “John of the Cross,” in *Classics of Western Spirituality*, ed. Kieran Kavanaugh (New York: Paulist Press, 1987), 162-209.

<sup>14</sup> Teresa of Avila, *Interior Castle*, trans. E. Allison Peers (New York: Doubleday, 1989). This work was written under compulsion, in snatches of time in a busy schedule, and Teresa never re-read or edited the work.

<sup>15</sup> Leech, *Soul Friend*, 67-75.

<sup>16</sup> *Ibid.*, 84-88.

spiritual direction can also be found in certain Protestant discipleship programs, as well as in Pentecostal practices like “listening prayer.”

### **Assessment/Approach**

Determining what point an individual or family is at on the spiritual spectrum is a daunting, if not impossible, task. One cannot simply classify or categorize any person according to case, for each is unique. God’s working is unique. The Divine manifestation is unique. God loves each personally and intimately, and the experience of this love is unparalleled. However, herein lies a paradox of direction; one must simultaneously embrace mystery as well as make some definitions. Thus, in beginning to define where an individual or family system is spiritually, it is helpful to have a framework from which the director can recognize the brushstrokes of spiritual maturity. The evaluation of spiritual life poses a challenge. Through more than two thousand years of history, the elasticity of Christianity has helped it accommodate changing times and cultures. However, this often causes challenges in identifying the image of a mature Christian.

According to William Bouwsma, maturity entails childlikeness, that is, an openness and propensity for radical growth and change, as opposed to childishness that rejects growth.<sup>17</sup> One psychologist offers this interesting proposition: whereas “Socrates encouraged his young followers to develop towards maturity; Jesus tried to reduce his to the level of children.”<sup>18</sup> Childhood not only entails growth, but welcomes the years with fearless interest and trust, poses simple but profound questions, and lavishly expresses wonder and astonishment. Perhaps this was Søren Kierkegaard’s insight when he wrote, “Therefore one does not begin by being a child and then becoming progressively more

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<sup>17</sup> William J. Bouwsma, “Christian Adulthood,” in *Adulthood*, ed. Erik Erikson (New York: W.W. Norton & Co., 1978), 91.

<sup>18</sup> Margaret Knight, *Honest to Man* (London: 1974), 41-42, in Bouwsma, “Christian Adulthood,” 83.

intimate (with God) as he grows older; no, one becomes more and more a child.”<sup>19</sup> This is part of the journey in spiritual direction, a discovery of one’s identity as a child of God. Thus, one begins to rise from under the strangle-hold of false identities and twisted attitudes in the spiritual life.

Likely, the premier indication of a healthy spirituality is the image of Christ, that “attaining to the whole measure of the fullness (*pleiroma*) of Christ.”<sup>20</sup> Interestingly, the *pleiroma* also occurs in Colossians 1, where it refers to the fullness of God dwelling in Christ, perhaps indicating that in the same way Christ fully embodies God, we fully embody Christ.

### Prayer

The key criterion for evaluating the spiritual life in spiritual direction is in the prayer life of the individual. The characteristics of prayer in a life indicate spiritual depth, struggle, and intimacy. Beatrice Bruteau suggests that ideal prayer “involves all our faculties, directed toward the whole of Reality and the *totality* of meaning: all of me toward and in all of It.”<sup>21</sup> Of course, the “all of It” and the “all of me” cannot be fully encountered in the sense that “It”, or God, is infinite, and mankind may never fully understand himself truly and completely. However, perhaps this definition of prayer can be simplified to “all that I know of me, directed toward all that I know of Him.” The path to knowing and joining oneself to God is also found through prayer. On this path, one discovers that true prayer begets true prayer, and consequently, the approach to, and result of, prayer is transformed.

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<sup>19</sup> Søren Kierkegaard, *Journals and Papers*, trans. Howard V. Hong and Edna H. Hong (Bloomington, 1967), 122, in Bouwsma, “Christian Adulthood,” 91.

<sup>20</sup> Eph 4:13.

<sup>21</sup> Beatrice Bruteau, “Insight and Manifestation: A Way of Prayer in a Christian Context,” *Contemplative Review* 16, no. 3 (Fall 1983): 18.

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<sup>21</sup> Beatrice Bruteau, “Insight and Manifestation: A Way of Prayer in a Christian Context,” *Contemplative Review* 16, no. 3 (Fall 1983): 18.

Bruteau refers to five different paths to knowing and joining oneself to God is also found through prayer. First is the “prayer of petition,”<sup>22</sup> where one brings his/her problems and needs to God and implores Him to do something about them. Then is the “prayer of appreciation,”<sup>23</sup> in which one’s attention has shifted from private concerns to a fascination and awe over experiencing another kind of reality. In petition, one sees Jesus as simply a means to “getting the goods,” but one also contemplates Jesus and is caught by his beauty. Eventually, one begins to enter into conversation, not speaking about Jesus, but addressing him in the first person. This is the “prayer of dialog,”<sup>24</sup> where friends talk to each other. In this prayer, the subject of conversation is insignificant, for the intercommunication is what matters. One is not seeking answers or things; one is experiencing a new way of being. As Bruteau says, “the intercommunication itself is a living reality and experienced in the moment as a living reality. There is living, energy-filled reality in it, moving both ways between the two persons.”<sup>25</sup> Then, one may enter into the “prayer of intimacy.”<sup>26</sup> In this prayer, what Jesus is communes directly with what one is. Traditionally, this is where language has been inadequate to describe what occurs. Descriptions and boundary lines begin to blur and the “two luminosities gradually grow together.”<sup>27</sup> There is a sense that Christ and self are moving together as a single unit. Prayer is no longer an event, nor is it an action at a particular time; prayer is living, and living is prayer. Bruteau writes, “Where is the individual self now? There is no way to answer, because the question no longer makes sense.”<sup>28</sup> As lofty as this prayer may seem,

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<sup>22</sup> Ibid., 21.

<sup>23</sup> Ibid.

<sup>24</sup> Ibid., 22.

<sup>25</sup> Ibid.

<sup>26</sup> Ibid., 24.

<sup>27</sup> Ibid.

<sup>28</sup> Ibid., 24-25.

there is another prayer beyond this— the “prayer of coincidence.”<sup>29</sup> In this prayer, one begins experiencing the consciousness of Jesus Himself. St. John of the Cross captures this thought, “your beauty will be my beauty; and therefore we shall behold each other in your beauty.”<sup>30</sup> In “intimacy” there is a blur in the distinction of persons, in “coincidence” the blur is complete, there seems to be a confusion of identity that is sourced in the insufficiency of language to express the experience.

The journey in prayer is tough and often filled with obstacles and distractions. Some of the more basic obstacles to life, spirit, and prayer must be resolved in order to mature through these steps of prayer. One obstacle is a refusal to forgive self or others. Another obstacle is a refusal to be reconciled; this continually stirs the waters of resentment and bitterness. Yet another obstacle involves anger, not just at others but also at self or at God. Any of these impediments will the soul and quench the Spirit, propagating, in the words of Kenneth Leech, a condition of “anti-prayer.”<sup>31</sup>

The inner noise of self-talk is often the greatest distraction of all. One may give little attention to the rhythms and patterns in his/her life, and ignore them in prayer, as well. People are often ignorant of their incapacity for prayer. In the words of Monica Furlong, “We have the audacity to suppose that prayer is something we ought to be able to do.”<sup>32</sup> Yet, true prayer can be nothing other than a gift of grace and a movement of God upon the being. This is typically a slow and impediment infested experience. At some point, as William Barry and William Connolly explain, “prayer comes to take on a

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<sup>29</sup> Ibid., 25.

<sup>30</sup> John of the Cross, *Spiritual Canticle*, stanza 36, in Bruteau, “Insight,” 26.

<sup>31</sup> Leech, *Soul Friend*, 169.

<sup>32</sup> Monica Furlong, *Christian Uncertainties*, (1975), 75, in Leech, *Soul Friend*, 168.

life of its own.”<sup>33</sup> Prayer becomes a living, breathing entity, and this union of spirit and Spirit, a reflection of Trinity.

### Wholeness and Integration

One of the common themes people hope to achieve through their efforts to attain the ideal spiritual life, particularly in more recent times, is wholeness or integration. This has been a longstanding theme of spiritual direction also. The supernatural result of a deepening prayer life is a deepening self-awareness. Thomas Merton boldly defined prayer as merely “awareness of one’s inner self.”<sup>34</sup> Perhaps his assumption is that only a person of prayer is aware of self, and the self-aware person must, of necessity, be a person of prayer. The two are inseparable. In prayer, one moves within oneself, and there encounters the darkness and the monsters. The inner being becomes life’s greatest battlefield. Dillard describes this journey:

In the deeps are the violence and terror of which psychology has warned us. But if you ride these monsters deeper down, if you drop with them farther over the world’s rim, you find what our sciences cannot locate or name, the substrate, the ocean or matrix or ether which buoys the rest, which gives goodness its power for good, and evil its power for evil, the unified field: our complex and inexplicable caring for one another, and for our life together here.<sup>35</sup>

After descending and discovering the frightening reality of self, one must go deeper still, to the most inner core. Merton, a Trappist monk well acquainted with this journey, writes:

If you descend into the depths of your own spirit...and arrive somewhere near the center of what you are, you are confronted with the inescapable truth that at the very root of your existence, you are in constant and immediate and inescapable contact with the infinite power of God.<sup>36</sup>

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<sup>33</sup> William A. Barry and William J. Connolly, *The Practice of Spiritual Direction* (San Francisco: Harper, 1982), 59.

<sup>34</sup> Leech, *Soul Friend*, 170.

<sup>35</sup> Annie Dillard, *Teaching a Stone to Talk* (New York: Harper & Row, 1982), 94-95, in *The Active Life*, Parker J. Palmer (San Francisco: Jossey-Bass, 1990), 30.

<sup>36</sup> Thomas Merton, “article title,” *Dublin Review* 223 (1949): 28, in Leech, *Soul Friend*, 170.



This is the stage where wholeness or integration begins. The false parts, the true parts, and the Divine presence are recognized. The healing, and the melding, and the transformation can begin, or have already begun. So to pray may be the definition of being truly human; through prayer, one begins the journey into the Eden walk, where God and naked humankind commune. Becoming human means becoming whole, or finding resolution to the problem wherein “sin diminish[es] and distort[s] one’s humanity.”<sup>37</sup>

### Listening

The place to start in prayer, in assessing life, and in spiritual direction, then, is listening. True listening, however, is excruciatingly difficult, particularly in the fast paced and cluttered world where people are constantly inundated with irrelevant advertisements and boisterous cell phone conversations. Many live in a turned-off mode where sensitivities have been cauterized. Barry and Connolly explain that the two fundamental tasks of a director are, first, to help the directee pay attention to God, and second, to help the directee recognize God’s actions.<sup>38</sup> This poses a challenge, as distracted people must now be encouraged to listen to someone who is invisible and mysterious. Once again, one is reminded that the simple act of listening is ultimately dependent upon an act of grace. True listening also involves employing the wholeness of one’s being. The entire person must find practical ways to enter stillness, because “prayer is not an activity of the mind, for God is not in the head. It is an activity of the whole person, and God is in the wholeness.”<sup>39</sup> Large portions of time in sessions for spiritual direction may be spent in

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<sup>37</sup> Leech, *Soul Friend*, 172.

<sup>38</sup> Barry and Connolly, *Practice*, 46.

<sup>39</sup> Leech, *Soul Friend*, 173.

silence. Silence may be the most productive time, for it encourages and trains one into a spirit of listening. There is a great temptation on the part of both novice director and directee to avoid this silence and to run from the sense of helplessness, poverty, and dependence it gives. But it is only in surrendering to silence that listening can actually begin. Francis Nemeck and Marie Combs encourage the following mode of operation, “When nothing is forthcoming we are to rest in nothing (*nada*): doing nothing, saying nothing.”<sup>40</sup>

By listening, the directee may be entering into a totally new way of living, a life transforming consciousness. Spiritual attentiveness is of prime importance. Nemeck emphasizes “fostering in directees maximum receptivity to God’s transforming and purifying love” to “assist directees to discern the obstacles which block the growth of Christ in them.”<sup>41</sup> To accomplish this, the director must also abide in the same spirit of listening, releasing the mentality of speculation in order to hear the Spirit revealing his/her needs. In listening, both director and directee enter into an opening, as opposed to an analyzing, a self-abandon, as opposed to a self-absorption.

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<sup>40</sup> Nemeck and Coombs, *The Way*, 90.

<sup>41</sup> *Ibid.*, 85.

## Finding God

### The Triple Way

#### History

As spiritual direction has developed over the centuries, it has been shaped by the systems of classical spiritual thought. Perhaps the premier system is “The Three Ways” (“De Triplici Via”) or “The Mystical Way.” The notion of dividing processes into three parts seems deeply rooted in mankind, and the tendency to see spiritual progress as having three stages has persisted through time. The Greek and Latin Fathers proposed three periods of the interior life. Clement of Alexandria, in his *Stromata*, conceived of three successive states: fear of God, faith and hope, charity and wisdom.<sup>42</sup> Origen also delineated three distinct stages: beginners, in whom inordinate passions lose their strength, proficients, in whom passions begin to die out under the abundance of grace in the Holy Spirit, and finally, the perfected.<sup>43</sup> Gregory the Great wrote of three steps, as well: the beginning of virtue, its progress, and its perfection.<sup>44</sup> Likewise, pagan religions also defined their principles in terms of threes. From the Neoplatonists came the principles of purgation, illumination, and perfection, and it was Pseudo-Dionysius who christianized this system.<sup>45</sup>

Many centuries transpired, before Hugh of St. Victor adopted the christianized threefold Dionysian themes. At the same time, Hugh added the powerful element of love as the chief means in advancing to union or perfection with God.<sup>46</sup> It was Bonaventure,

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<sup>42</sup> Reginald Garrigou-Lagrange, “The Three Ages of the Interior Life,” in *Scriptural Value of Lenten and Easter Liturgical Texts*, ed. Edward M. Wilson (1955), 4, Collections of St. Bonaventure Library, St. Bonaventure, N.Y.

<sup>43</sup> *Ibid.*, 4.

<sup>44</sup> Pascal Parente, “The Ascetical Life,” in Wilson, *Lenten Texts*, 4.

<sup>45</sup> *Ibid.*, 69.

<sup>46</sup> Rorem, Paul, ed. *Pseudo-Dionysius in Classics of Western Spirituality* (New York: Oxford University Press, 1993), 217.

however, who transformed Dionysius' static model into a dynamic one. Bonaventure was a genius in joining both dogmatic and ascetic theology. Paul Rorem explains that Bonaventure's creative work is the culmination of the Victorine integration of Dionysian darkness into the Western legacy of love for Christ crucified. Rorem also indicates that his effort successfully meshes Dionysius' apophatic cloud with Francis' kataphatic stigmata.<sup>47</sup> Thus, through Bonaventure, The Triple Way took on a new and powerful form—a form that utilized all the major streams of earlier Western mysticism: Augustinian, Dionysian, Gregorian, Cistercian, Victorine.<sup>48</sup>

The influence of The Triple Way impacts not only much spiritual thinking and writing, but also the philosophy of spiritual direction. Contemporary theological discussions of The Triple Way include: Adolphe Tanquerey in *The Spiritual Life*,<sup>49</sup> Reginald Garrigou-Lagrange in *The Three Ways of the Spiritual Life*,<sup>50</sup> and Louis Bouyer in *Introduction to Spirituality*.<sup>51</sup> Writers that give The Triple Way attention from a psychological viewpoint include: Evelyn Underhill in her classic *Mysticism*,<sup>52</sup> Adrian van Kaam in *The Dynamics of Spiritual Self-Direction*,<sup>53</sup> Gerald May in *Care of Mind Care of Spirit*,<sup>54</sup> and Benedict Groeschel in *Spiritual Passages*.<sup>55</sup> Others have even redefined

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<sup>47</sup> Rorem, *Pseudo-Dionysius*, 220.

<sup>48</sup> Bernard McGinn, *The Flowering of Mysticism*, vol. 3 of *The Presence of God: A History of Western Christian Mysticism* (New York: Crossroad, 1998), 93.

<sup>49</sup> Adolphe Tanquerey, *The Spiritual Life: A Treatise on Ascetical and Mystical Theology*, trans. Herman Branderis (Tournai, Belgium: Desclee, 1932).

<sup>50</sup> Reginald Garrigou-Lagrange, *The Three Ways of the Spiritual Life* (Westminster, Md.: Newman, 1950).

<sup>51</sup> Louis Bouyer, *Introduction to Spirituality*, trans. Mary Perkins Ryan (New York: Desclee, 1961).

<sup>52</sup> Evelyn Underhill, *Mysticism: The Nature and Development of Spiritual Consciousness* (Oxford: Oneworld, 1999).

<sup>53</sup> Adrian van Kaam, *Dynamics of Spiritual Self Direction* (Denville, N.J.: Dimension Books, 1976).

<sup>54</sup> Gerald May, *Care of Mind / Care of Spirit: A Psychiatrist Explores Spiritual Direction* (San Francisco: Harper, 1992).

<sup>55</sup> Benedict J. Groeschel, *Spiritual Passages: The Psychology of Spiritual Direction* (New York: Crossroad, 1999).

The Three Ways with new terms, like Donald Hands and Wayne Fehr's use of "uncovery," "discovery," and "recovery."<sup>56</sup>

Despite the fact that The Triple Way is not primarily based on theological considerations or restricted to Christianity, it has provided a framework for the spiritual journey that is difficult to explain otherwise. Each of the three stages, Purgation, Illumination, and Union, are like hooks on which solid, scriptural truths can be hung.

### **The Way of Purgation**

The first stage in The Triple Way is the way of purgation. Although there are two other progressive stages, a certain amount of overlap and interplay occurs among the three. Purgation is the process through which an individual is cleansed and freed of the impediments that block the soul's intimate union with God. Bonaventure writes that the purgative way is practiced in sorrow, but finished in love.<sup>57</sup> Bonaventure also implores all humanity to consider the condition of our hearts before God:

Have you thought of where you are?  
What was once close to heaven itself is now clawing at the gates of Hell!  
Have you considered what composes you?  
What was once beautiful and pure is now ugly and filthy!  
Have you meditated on what you are?  
What was once free is now a slave!<sup>58</sup>

*The Cloud of Unknowing* describes the beginning condition of mankind; every person is occupied with the "foul and fetid lump of himself," and this is what must be overcome.<sup>59</sup>

*The Cloud* also describes the wretched condition of a person entering purgation, "...if a man would be God's perfect disciple and taught by him on the mountain of perfection, he is nearly out of his mind with sorrow, so much so that he weeps and wails, strives with

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<sup>56</sup> Donald R. Hands and Wayne L. Fehr, *Spiritual Wholeness for Clergy: A New Psychology of Intimacy with God, Self and Others* (Bethesda, Md.: Alban, 1993), 15.

<sup>57</sup> Bonaventure, *The Triple Way*, ed. William I. Joffe (Paterson, N.J.: Saint Anthony Guild Press, 1956), 12.

<sup>58</sup> *Ibid.*, 27.

<sup>59</sup> Anonymous classic *The Cloud of Unknowing*, ed. James Walsh (Mahwah, N.J.: Paulist Press, 1981), 204.

himself, denounces and heaps curses upon himself.<sup>60</sup>

At the turning point between the purgative way and the illuminative way there is an experience which St. John of the Cross describes as the “dark night of the senses.”<sup>61</sup> Though the dark nights are intensely painful, they lead to inevitable joy. In the following excerpt from *The Living Flame of Love*, both the pain and the joy coexist:

O living flame of love  
That tenderly wounding my soul  
In its deepest center...  
O sweet cautery  
O delightful wound  
O gentle hand! O delicate touch  
That tastes of eternal life  
And pays every debt!  
In killing you changed death to life.<sup>62</sup>

### **The Way of Illumination**

The stage of illumination is characterized by contemplation and knowledge of God. Bonaventure explains that “this heavenly light must first illumine all of our forgiven sins; then it must spread out to cover the gifts that God has given us; lastly, it must reflect on the rewards that He has promised us.”<sup>63</sup> To enter illumination is to bask in the immensity of God’s gracious goodness and reality.<sup>64</sup> Wayne Teasdale reasons that the intention of gaining knowledge of God is like a five-year-old trying to understand relativity; what is needed is an interior explosion of consciousness at the center of one’s being in God.<sup>65</sup>

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<sup>60</sup> Ibid., 204.

<sup>61</sup> *Westminster Dictionary of Christian Spirituality*, # (4th, 2d, 11th, etc.) ed., s.v. “catharsis.”

<sup>62</sup> John of the Cross, *John of the Cross*, 293-294. (you already gave all the other info) ed. Kieran Kavanaugh. New York, Paulist Press, 1987), 293-294.

<sup>63</sup> Bonaventure, *Triple Way*, 13.

<sup>64</sup> Wayne Teasdale, “The Mystical Approach to Life,” *Studia Mystica* 6, no. 3 (Fall 1983): 55.

<sup>65</sup> Ibid., 56.

Many writers deal with the struggle to be illuminated in terms of an ineffable God.

Perhaps a large part of illumination is attained through dismantling all we thought God to be. Dionysius himself explains the compromised position to be held:

But as for now, what happens is this. We use whatever appropriate symbols we can for the things of God. With these analogies we are raised upward toward the truth of the mind's vision, a truth which is simple and one. (Then) we leave behind us all our own notions of the divine. We call a halt to the activities of our mind's and, to the extent that is proper we approach the ray which transcends being.<sup>66</sup>

In purgation, the lens of how one sees reality has been significantly cleansed.

Finally, there is room to receive the Divine sketches, many of which are dark and unclear.

Though the spiritual life may be filled with darkness, there are also bright times. The theme throughout *The Cloud of Unknowing* is the darkness and ineffability of God;

however, it also speaks of the rays that pierce through the cloud:

Then perhaps it will be his will to send out a ray of spiritual light, piercing this cloud of unknowing between you and him, and he will show you some of his secrets, of which many may not or cannot speak. Then you shall feel your affection all aflame with the fire of his love, for more than I know how to tell...<sup>67</sup>

## **The Way of Union**

Of the three ways, union is by far the most probed and fondled. Something about union with the Almighty seems to irresistibly draw mankind. It is just as Meister Eckhart's quote of St. Bernard of Clairvaux goes, that "God, despite himself, is ever hanging over us some bait to lure us into him."<sup>68</sup> Union is the ultimate goal of The Triple Way, and of mysticism. Union can be defined as the ecstatic experience through which the soul is radically transformed in God and mysteriously radiates His presence.

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<sup>66</sup> Rorem, *Pseudo-Dionysius*, 210.

<sup>67</sup> *Cloud of Unknowing*, 174-175.

<sup>68</sup> Bernard of Clairvaux, quoted in Meister Eckhart, "Sermon on St. Benedict's Day," quoted in David Mueller, "The Mystical Union in the Sermons of Meister Eckhart," *Science, Faith, and Revelation*, ed. Bob E. Patterson (Macon, Ga.: Mercer University Press, 1979), 79.

Bonaventure says union is highly mysterious and beyond description:

All intellectual activities must be left behind and the height of our affection must be totally transferred and transformed into God. This, however, is mystical and most secret, which no one knows except him who receives it, no one receives except him who desires it, and no one desires except him who is inflamed in his very marrow by the fire of the Holy Spirit...<sup>69</sup>

In the state of union, the rules of this world do not apply, and the seemingly eccentric descriptions may alarm certain people. Jan van Ruusbroec's eloquent description of union as a wanton and unrestrained experience is sure to bring discomfort to many:

Nevertheless, all loving spirits are one enjoyment and one beatitude with God, without difference, for that blessed state of being, which is the enjoyment of God and of all his beloved is so simple and undifferentiated that there is within it neither Father nor Son nor Holy Spirit as regards the distinction of Persons, nor is there any creature either. Rather, all enlightened spirits are there raised above themselves into a modeless state of blissful enjoyment which overflows whatever fullness any creature has ever received or ever could receive. There all exalted spirits are, in their superessential being, one enjoyment and one beatitude with God, without difference. This beatitude is so simple and undifferentiated that no distinction could ever enter within it.<sup>70</sup>

There is also an irresistible quality to union that pulls on each spirit, despite the fearsome descriptions of that state of being. Ruusbroec speaks of that "dark stillness in which all lovers lose their way," and then "flow into the wild waves of the Sea, from which no creature could ever draw us back."<sup>71</sup> In this "Sea," the self seems lost, and so do all descriptions of the self. In *The Ascent of Mount Carmel*, St. John of the Cross speaks of this loss:

I abandoned and forgot myself  
Laying my face on my beloved  
All things ceased; I went out from myself,

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<sup>69</sup> Bonaventure, *Bonaventure*, in *Classics of Western Spirituality*, ed. Ewert Cousins, (New York: Paulist Press, 1978), 113.

<sup>70</sup> Ruusbroec, John, *John Ruusbroec*, in *Classics of Western Spirituality*, trans. James A. Wiseman (New York: Paulist Press, 1985), 226.

<sup>71</sup> *Ibid.*, 152.



Leaving all my cares  
Forgotten among the lilies.<sup>72</sup>

The issue of loss of self has been highly debated throughout history. Is the union a mere union of wills? Is it an essential union where self is absorbed into God? Dealing with the paradox involving union has become a point of contention for many. The description of union became a dilemma for Meister Eckhart, who was eventually condemned by the Catholic Church the early 14<sup>th</sup> century as a heretic.<sup>73</sup> His writings, though the source of great controversy, continue to have great influence today. Still there are statements, such as this quoting of Dionysius, that concern many people, “Thus Dionysius says: This race is precisely the flight from creature to union with the uncreated. When the soul achieves this, it loses its identity, it absorbs God and is reduced to nothing, as the dawn at the rising of the sun.”<sup>74</sup>

One of Eckhart’s disciples, John Tauler, though more cautious than Eckhart, has also made statements that endorse absorption, “In this absorption all like and unlike is lost. In this abyss the spirit loses itself and knows neither God nor itself, neither like nor unlike. It knows nothing, for it is engulfed in the oneness of God and has lost all differences.”<sup>75</sup> Others, however, seek to erase the ambiguity and clarify that union does not mean absorption. In this vein, Ruusbroec says, “I just said that we are one with God, something to which Scripture bears witness. I now wish to say that we must forever remain different from God, which is also taught us by Scripture. We must understand and

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<sup>72</sup> John of the Cross, *John of the Cross*, 56. Kavanaugh, 56.

<sup>73</sup> Edmund Colledge and Bernard McGinn, trans. and ed., *Meister Eckhart: The Essential Sermons, Commentaries, Treatises, and Defense*, in *Classics of Western Spirituality* (New York: Paulist, 1981), 11-13.

<sup>74</sup> Meister Eckhart, quoted in Raymond B. Blakney, *Meister Eckhart: A Modern Translation* (New York: Harper, 1941), 89, in “The Mystical Union in the Sermons of Meister Eckhart,” David L Mueller, in *Science, Faith, and Revelation*, ed. Bob E. Patterson (Macon, GA: Mercer University Press, 1979), 76.

<sup>75</sup> John Tauler, Sermon 28, *Homo Spiritualis*, trans. Steven Ozment, 38, in *Ordinary Mysticism*, Dennis Tamburello (New York: Paulist Press, 1996), 117.

experience both these points if we are to be on the right path.”<sup>76</sup>

Whatever the case, it seems a formidable task to try describing the mystical paradox of the union experience. Teasdale recognizes that the language from each tradition is drawn from the “common experience, from ordinary life: it is not equipped to adequately describe mystical awareness at its zenith.”<sup>77</sup> Long ago, St. John of the Cross gave poetic support for the inadequacy of descriptive language:

Deep-cellar'd is the cavern  
Of my hearts love, I drank of him alive;  
Now, stumbling from the tavern,  
No thoughts of mine survive,  
And I have lost the flock I used to drive.<sup>78</sup>

### The Dark Nights

#### Night of the Soul

As a person begins to pass from illumination to union, St. John of the Cross describes another phenomenon known as the “dark night of the soul [or sense].”<sup>79</sup> After the soul has been unencumbered through purgation, and now enlightened regarding the beauty of God through illumination, the intense longing for God is accompanied by His stark absence. Note St. John’s agony in *The Dark Night*:

Poor, abandoned, and unsupported by any of the apprehensions of my soul (in the darkness of my intellect, the distress of my will, in the affliction and anguish of my memory) left to darkness in pure faith, which is a dark night for these natural faculties, and with only my will touched by the sorrows, afflictions, and longings of love of God, I went out from myself. That is, I departed from my low manner of understanding, and my feeble way of loving, and my poor and limited method of finding satisfaction in God.<sup>80</sup>

<sup>76</sup> Ruusbroec, *John Ruusbroec*, 174.

<sup>77</sup> Teasdale, “Mystical Approach,” 56.

<sup>78</sup> John of the Cross, *Poems of St. John of the Cross*, ed. Roy Campbell (New York: Pantheon, 1951).

<sup>79</sup> St. John’s use of the term “dark night” is rooted in literal experience. Caught up in the turmoil of Teresa’s reform, he was imprisoned for nine months in a six-by-ten-foot cell. The only source of light was a two-inch window. While imprisoned, he wrote the majority of his poems, including the first 31 verses of *Spiritual Cantic*.

<sup>80</sup> John of the Cross, Kavanaugh, 200.

Though there are not direct references to these nights in Scripture, inferences of such spiritual states can be found particularly in books like Job or the Psalms.<sup>81</sup> Typical symptoms of the dark night include a sense of the absence of God, dryness in prayer, disillusionment with one's understanding of the Christian life, and a spiritual loss of control.<sup>82</sup> These conditions can also easily be symptoms of negative conditions, such as depression, illness, or sin. With contemporary general familiarity with Sanjuanist<sup>83</sup> writings, it has also become popular for people to say they are going through a dark night when they experience grief, stress, or even some trivial problem. The dark night of the soul, though it may include these problems, is much more; it is a complete spiritual reorientation. The fruit of this experience is to see self and God as never before. Foster explains that, through the dark night, one gains "a profound and holy distrust of all superficial drives and human strivings. We know more deeply than ever before our capacity for infinite self deception."<sup>84</sup> In spite of the spiritual suffering, there comes a sense that something is very right, albeit terrible, and when the suffering finally bears the intended fruit, God rescues us through illuminative or unitive experiences. Benedict Groeschel says of this transition, "the cause of darkness may still remain and tears of sorrow may still flow, but in spite of it all a new soft and gentle light is rising in the inner being of the individual."<sup>85</sup>

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<sup>81</sup> For example: Job chapter 3 and Psalm 22:1-2.

<sup>82</sup> Nancy Pfaff, "Spiritual Direction and the Dark Night of the Soul," *Presence* 4, no. 2 (May 1998): 34.

<sup>83</sup> The term "Sanjuanist" is sourced in the original Spanish to the name San Juan de la Cruz or St. John of the Cross.

<sup>84</sup> Richard Foster, *Prayer: Finding the Heart's True Home* (San Francisco: Harper, 1992), 24, in Pfaff, "Direction and the Dark Night," 41.

<sup>85</sup> Benedict J. Groeschel, *Spiritual Passages* (New York: Crossroad, 1992), 154, in Pfaff, "Direction and the Dark Night," 41.

## Night of the Spirit

Before the experience of full union, another dark night is needed—the night of the spirit. There are two levels of psyche requiring purification. The first is the soul or sense, which has to do with interior and exterior senses such as imagination, memory, feelings, and intellect. These senses can be pleasant consolations, but also distractions. The second level of psyche that must be purified is the spirit. The night of the spirit involves a cleansing of intelligence and will. This night is much more painful than the former.<sup>86</sup>

While the first night, the night of the soul, is like clipping seeds off weeds, the second night, the night of the spirit, is like ripping up the unseen roots.<sup>87</sup> The “night” may be mingled with depression, for the two states hold much in common:

Depression demands that we reject simplistic answers, both “religious” and “scientific,” and learn to embrace mystery, something our culture resists. Mystery surrounds every deep experience of the human heart: the deeper we go into the heart’s darkness or its light, the closer we get to the ultimate mystery of God.<sup>88</sup>

However, night and depression do not necessarily co-exist. For someone experiencing the dark night of the spirit, life may seem fine at both work and play, but an indication of night may be found in the starkness of one’s prayer life. Though the spirit wants nothing but God, it experiences a loss of Him. It thus faces an “oppressive undoing,” where God’s love assails, strikes, disentangles, dissolves, divests, chastises, afflicts, and purifies it.<sup>89</sup>

Trouble in the prayer life, however, is a likely indication of progress. As Marie Dyckman and Patrick Carroll explain, “difficulty in prayer often marks the beginning of

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<sup>86</sup> Benedict M. Ashley, *Spiritual Direction in the Dominican Tradition* (New York: Paulist, 1995), 111-113.

<sup>87</sup> Thomas Dubay, *Fire Within* (San Francisco: Ignatius Press, 1989), 170.

<sup>88</sup> Parker Palmer, “All the Way Down: Depression and the Spiritual Journey,” *Weavings* 13, no. 5 (September-October 1998): 35.

<sup>89</sup> St. John of the Cross, quoted in Dubay, *Fire Within*, 169.

real prayer... Through darkness, aridity, and emptiness we are called to a new form of prayer, a new stage of our relationship with the Lord.”<sup>90</sup> The result of this struggle in the second night means the spirit is freed from:

Dullness of mind  
Lack of sensitivity to the Spirit  
Distracted and inattentive inner life  
Lowly and natural mode of communion with God  
Feeble and imperfect knowledge of God  
Remnants of pride  
Undue security in spiritual experiences<sup>91</sup>

The Three Ways and The Dark Nights are not as clear and orderly as they are often made out to be. There is significant overlap and the stages are not always linear. The path for each person is a little different from that of any other. The degrees to change in each area of the spiritual life may vary before moving to another stage. As complicated as these stages and processes may seem, great relief comes through understanding that human effort is not sovereign in spiritual progress. Grace begins the path and grace continues the path—nothing occurs without grace.

### **Entering the Calm**

The realization that progress only comes through grace is the beginning of entering the calm. The calm is an experience far from normal in today’s bustle and clutter. Many people allow their environments and their inner conditions to harass them away from “graced calm,” that level of calm that comes only from God. Adrian van Kaam captures this turmoil:

He allows his managing, controlling ego to dominate his life, he reduces or eliminates any possibility of being open to the Spirit. Graced aspirations can no longer guide, modify and mellow the aggressive ambitions of his ego. He

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<sup>90</sup> Katherine Marie Dyckman and L. Patrick Carroll, *Inviting the Mystic Supporting the Prophet: An Introduction to Spiritual Direction* (New York: Paulist, 1981), 62-63.

<sup>91</sup> St. John of the Cross, quoted in Dubay, *Fire Within*, 168.

becomes driven by isolated ambitions that blind and overwhelm him. No room is left in the personal sphere for the gentle, stilling influence of the Spirit...<sup>92</sup>

Oddly, mankind continues to run from God, avoiding him like some distant friend. Perhaps one thinks, "If I were to stop and call, it would take too much time, for so much water has passed under the bridge since we last talked." Thus, one procrastinates, missing the calm. Perhaps one avoids him out of fear—fear that since so many things demand attention, time with him seems beyond reckoning, for life is already overwhelming enough.

May explains that "any attempt to produce anything in meditation is bound to be a hindrance...meditation must ideally be a situation in which trying stops and things are allowed to settle."<sup>93</sup> He also quotes the advice of St. John of the Cross: "In order to arrive at being everything, desire to be nothing. In order to arrive at knowing everything, desire to know nothing."<sup>94</sup>

Upon entering the calm, one is content to surrender, to yield, and to wait. Prayer takes on a new atmosphere. It is not seeking relief or cure. It is "inarticulate communion" and "silent gazing" which may lead one to spontaneously slip into the prayer of orison. Orison, according to Evelyn Underhill, has nothing to do with petition, it has no forms, but rather, it is the mere yearning of the soul, wordless prayer.<sup>95</sup> Such prayer cannot be conjured; rather, it is a graced experience. The person experiencing this type of prayer life is living beyond circumstances and situations.

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<sup>92</sup> van Kaam, *Spiritual Self Direction*, 511.

<sup>93</sup> Gerald May, *Will and Spirit: A Contemplative Psychology* (Cambridge: Harper & Row, 1982), 57.

<sup>94</sup> St. John of the Cross, *Ascent of Mount Carmel*, in *Complete Works*, ed. E. Allison Peers (London: Westminster, 1953), in May, *Will and Spirit*, 57.

<sup>95</sup> Underhill, *Mysticism*, 323. This classic work is likely the premier evaluation of mysticism. The book expands consciousness. It also maintains intellectual stamina and is sensitive to the sciences.

To begin to enter the calm is a gift of grace. Grace transforms one's psyche and spirit, quieting "his vital drives and sensate feelings sufficiently to leave him open for the inspirations of the Spirit and the aspirations that blossom forth from them."<sup>96</sup>

Such stilling is far from being paralyzing. Even in the depths of contemplation, vital action occurs, because vital action includes the spirit of contemplation. In the spirit of one who is stilled, much is happening, for it is in the stilling that revelation comes. To "be still" precedes "knowing God."<sup>97</sup>

### New Meaning

In any person's spiritual journey, particularly when that person is dealing with the painful circumstances of life, a sense of meaning is inseparable from a sense of hope, and hope is at the root of growth. However, in direction, meanings cannot be taught. Meaning is not systematic and is often shrouded in mystery. Meaning is intensely personal and oblique. Each individual must personally discover meanings through the new sense of openness and calm that has been established through the environment of direction.

Unavoidably, everyone must live with a certain degree of tension between mystery and meaning. All people, however, long to assign some meanings to their experiences, particularly the painful ones. Assigning meaning is critical to one's spiritual progress. Tournier says of those who get stuck in life because of an inability to find meaning:

Patients who are skeptics endure a threefold suffering. They suffer from their disease, and they suffer on account of its meaninglessness for them. It is in their eyes nothing but a more or less serious vexation, the result of blind chance. They

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<sup>96</sup> van Kaam, *Spiritual Self Direction*, 510.

<sup>97</sup> Psalm 46:10

suffer again because it suspends their lives. They wait passively for their cure in order to begin living again.<sup>98</sup>

The age-old vexation for the skeptic in pain has been the entrapping line of questioning that begins, “If the suffering is from God, how can God be both powerful and good? If the suffering is not from God, how can there be meaning in it?” Such logic seems impeccable, but guarantees that either way one decides to answer, one will lose. By taking the skeptic’s attitude, the individual freezes his/her growth and stunts all relationships. There is another way, the way of faith—faith in a God who, in the words of Carlo Carretto, “annihilates himself for love, in Christ, and to save his creatures pays with his blood.”<sup>99</sup> It is in embracing such an image of God that we are able to step into the mystery of suffering and begin to discover meaning; it is a difficult journey, but not a meaningless one. Carretto found meaning in this way:

...it is difficult to understand how he loves, and how he shows his love by making you suffer is the secret hidden in the ages.

I died for you – he tells me on Calvary – now learn to die a little for me.

By dying you will learn the secret.

But you will only learn it if you die for love like me.<sup>100</sup>

In this struggle, one must take care to nurture and cherish hope, for often the revelations seem exceedingly rare, especially considering how long one has waited for them. Wise direction is careful not to harm the smoldering wick, but instead, to find life in the midst of death. Sandra Cronk states, “each of the people who experienced a symbolic confrontation with death had to find a symbolic experience of new life in order to enter fully into his or her way of being in actual daily living.”<sup>101</sup>

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<sup>98</sup> Paul Tournier, *The Healing Spirit* (Westchester, Ill.: Good News, 1979), 19.

<sup>99</sup> Carlo Carretto, *Why O Lord? The Inner Meaning of Suffering* (Maryknoll, N.Y.: New York: Orbis, 1985), 53.

<sup>100</sup> Carretto, *Meaning of Suffering*, 59.

<sup>101</sup> Sandra Cronk, *Dark Night Journey* (Philadelphia, Penn.: Pendle Hill, 1993), 72, in Pfaff, “Direction and the Dark Night,” 36.



## Transformation

Although the ultimate goal of direction is not positive results, but rather union with the Divine, positive transformational outcomes do occur, as well. Some may view these outcomes as mini-conversions in the inner life, for there are many types and levels of conversion. Walter Conn refers to a multi-dimensional view of conversion involving moral, affective, cognitive, and religious conversions. The ensuing changes that follow each are consecutively a new way of living, a new way of loving, a new way of knowing, and a new way of being.<sup>102</sup> Certainly these play a part in spiritual direction as well, for direction is holistically focused.

Dallas Willard gives insight into another popular concept related to transformation, specifically, integration: that being, integration:

The condition of normal human life is one where the inner resources of the person are weakened or dead and where the factors of human life do not interrelate as they were intended by their nature and function to do. This is sin in the singular: not an act but a condition. It is not that we are wrong, but that our inner components are not “hooked up” correctly any longer. Our thinking, our feeling, our very bodily dispositions are defective and connected wrongly with reference to life as a whole.<sup>103</sup>

Integration is difficult to define, because in defining, according to Joel Giallanza, its dynamic quality would atrophy. Integration is never static, but continually in progress, bringing the various parts into an organic wholeness. The four parts that comprise this wholeness are: self-knowledge, self-articulation, self-recognition, and self-acceptance. But these elements are integral to one another, strengthening or weakening each other, and supporting each other without solid lines of demarcation.<sup>104</sup>

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<sup>102</sup> Walter Conn, *The Desiring Self: Rooting Pastoral Counseling and Spiritual Direction in Self-Transcendence* (New York: Paulist, 1998), 116.

<sup>103</sup> Dallas Willard, “Spiritual Disciplines, Spiritual Formation, and the Restoration of the Soul,” *Journal of Psychology and Theology* 26, no. 1 (Spring 1998): 104-105.

<sup>104</sup> Joel Giallanza, “Integration,” 32-33.

Of course, the director must be a person who has undergone significant transformation, as well. This means the director has come to some moderate level of health through the process of integration. In the description of Elaine Korthals, “To be the perfect spiritual director means that one must reflect in one’s being the Trinitarian dynamic of self-knowledge, acceptance, and mission as a part of a responsive relationship that is centered in love and truth.”<sup>105</sup> This does not necessarily mean that the director has “arrived” or become “enlightened” in the popular sense. David Lonsdale tells of how the most effective of spiritual directors often appear to be very fragile themselves, and may seem to be in more turmoil than the average person. The French director Abbe Marie-Joseph Huvelin was an example of this. He offered direction while lying on his couch in a dark room, suffering from gout, migraines, and other afflictions. His notebooks indicate that he suffered depression and thoughts of suicide. However, he was director to great spirits like Charles de Foucauld and Baron von Hugel.<sup>106</sup> Perhaps this is a picture of the director who is most deeply acquainted with inner self—a soul who is truly a “wounded healer.”<sup>107</sup>

The central aspect of transformation in spiritual direction might be described as transcendence. This means moving away from the usual and natural life, and moving toward living life on another level. This transcendence changes a person both inwardly and outwardly. In regard to the self, the individual is moved from an unproductive self-focus to a fruitful centering where one sees the truth of oneself. In regard to others, the individual is moved from unproductive distraction to having eyes opened to see as Christ sees, and to see God presently within oneself and others. The ultimate definitions come

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<sup>105</sup> Elaine Korthals, “The Key to Spiritual Direction,” *Review for Religious* (November-December 1986): 908.

<sup>106</sup> David Longsdale, “A Paradox in Spiritual Direction,” *Review for Religious* (July-August 1986): 567.

<sup>107</sup> Henri J. M. Nouwen, *The Wounded Healer* (New York: Image/Doubleday, 1990).

from God, not man, and they are found in transcending beyond the surface levels of life and entering into a biblical reality.

Transformation can be seen as a progressive enlightenment that moves inward. This enlightenment stimulates a new way of existing. The following diagram could be viewed as a grotesquely abbreviated rendering of St. Teresa's "inner castle," showing the different places of existence.

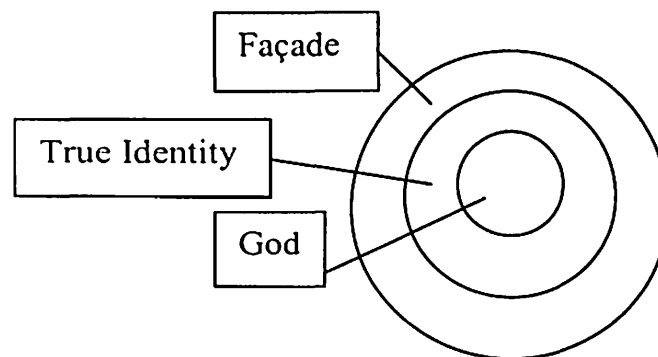


Figure 3.1. Levels of Existence

First, wisdom warrants some clarity—the diagram does not seek to imply that the individual is God, but that God dwells at the core of the individual. In addition, the lines of delineation are not as cleanly cut as the diagram portrays. Each person is a mixture of the above, some living more toward the outside, and some, toward the inside. One exists more fully within some aspects of life than within other aspects of life. However, it seems evident that most of humanity exists predominantly in the realm of façade. Humankind recognizes self and others in terms of jobs, roles, credentials, possessions, experiences, and appearances. Each evaluates his/her own significance and others' value by the temporal externals. This is what Nemeck refers to as a life of "self-alienation."<sup>108</sup> The individual caught in this system is plagued with feelings of insecurity,

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<sup>108</sup> Nemeck, *The Way*, 57.

inadequacy, and inferiority. This is devastating to his/her ability to be intimate.

Philomena Agudo addresses this problem:

Alienation from self increases the need to be loved and accepted but decreases the capacity to love. Self-hatred erects a barrier to satisfactory relationships. When an individual hates himself or herself, he or she operates by means of pretense and deceit. Since these means cannot be hidden from self, contempt for self increases. Self-contempt, self-alienation, and self-hatred are expressed in hostility towards others. Such hostility breeds so much anxiety and guilt that an individual finds it impossible to enjoy any relationship at all...<sup>109</sup>

So in self-alienation, not only is intimacy with others thwarted, but also intimacy with God. Thus, spiritual direction aims to aid a person or group in becoming liberated and unencumbered, that they might find themselves— their true selves— and find the true God who is speaking at the center of their beings. Such a life is an existence at a totally different level.

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<sup>109</sup> Philomena Agudo, *Intimacy with Self vs. Self-Alienation*, in *Intimacy* (Affirmation Books, 1978), 20-21, in Nemeck, *The Way*, 58.

## CHAPTER 4

### COLLABORATING WITH THE FAMILY: THE APPROACH OF NARRATIVE THERAPY

#### Introduction

#### Description of Narrative Therapy

Narrative therapy is a recently evolved approach to therapeutic counseling that began gaining ground in the early 1980s. Because narrative therapy has its roots in Australia, its chief progenitor, Michael White, has affectionately termed it a “Down Under therapy style.” White also refers to narrative therapy as a “therapy of literary merit,” emphasizing its creative authoring of new stories.<sup>1</sup>

The central tenet which drives narrative therapy is that human life is based on stories, and these stories are written out of the experiences of life. Thus, each person plays a fundamental role in the creation of his/her realities, though such realities may be subjective interpretations of experience. William Madsen captures this practice:

Human beings organize their experiences in the form of stories. Narrative or life stories provide frameworks for ordering and interpreting our experiences in the world. At any point, there are multiple stories available to us and no single story can adequately capture the broad range of our experience. As a result, there are always events that fall outside any one story. However, over time particular narratives are drawn upon as an organizing framework and become the dominant story. These dominant stories are double-edged swords.<sup>2</sup>

The primary idea in narrative therapy, then, is that each person has many choices or versions of reality at his/her disposal. Like a “double-edged sword,” each version has the potential benefit of giving meaning, but also the danger of giving negative meaning. The answer for those trapped in a hurtful story, therefore, is to discover the other stories

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<sup>1</sup> Michael White and David Epston, *Narrative Means to Therapeutic Ends* (New York: Norton, 1990), 14.

<sup>2</sup> William C. Madsen, “Inviting New Stories: Narrative Ideas in Family-Centered Services,” *Journal of Systemic Therapies* 18, no. 3 (1999): 7.

available to them. People tend to only notice certain details of their lives, and then get locked into particular scenarios. They then force interpretations of future events to fit the established grid-work. The resulting problem is an unbeneficial story which, besides being inflexible and limiting, may not even be sound. Madsen charts the problematic tendency of getting locked into a particular story:

Narratives organize our field of experience, promoting selective attention to particular events and experiences, and selective inattention to other events and experiences. In this way, much of our lived experience goes unstored, it's obscured and phenomenologically does not exist. Particular narratives can become problematic when they constrain us from noticing or attending to experiences that might otherwise be quite useful to us.<sup>3</sup>

Many people suffer from dominant stories that do not fit their identities or experiences because they are impacted by “cultural discourses” that seek to conform people to their agendas. As Gerald Monk writes, “The newly born child is instantly born into a ‘cultural soup.’ From a narrative perspective, problems may be seen as floating in this soup.”<sup>4</sup> Few are aware of the powerful role this “cultural soup,” or discourse, plays in the formation of a person’s views and values. Everyone has a place in propagating these discourses. A child is taught not just by parents and grandparents, but also by siblings and schoolteachers, mass media and books. This “soup” determines what he sees, values, and lives for. The resulting narrative then crowds out aspects that might have been more appropriate for an individual, fostering a continual source of frustration. According to Michael White and David Epston, the simple reason:

That the person’s experience is problematic to him because he is being situated in stories that others have about him and his relationships, and that these stories are dominant to the extent that they allow insufficient space for the performance of the person’s preferred stories. Or we would assume that the person is actively

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<sup>3</sup> Ibid.

<sup>4</sup> Gerald Monk, “How Narrative Therapy Works,” in *Narrative Therapy in Practice: The Archeology of Hope*, ed. Gerald Monk et al. (San Francisco: Jossey-Bass, 1997), 27.

participating in the performance of stories that she finds unhelpful, unsatisfying, and dead-ended, and that these stories do not sufficiently encapsulate the person's lived experience or are very significantly contradicted by important aspects of the person's lived experience.<sup>5</sup>

The basic goal of narrative therapy is not to be a "problem-solving orientation," for such an orientation may be based merely on the premise of "pleasure seeking."<sup>6</sup> Rather, the goal of narrative therapy is to create an entirely new reality with far-reaching influence. White explains that the effort in narrative therapy is to:

Bring forth and 'thicken' stories that did not support or sustain problems...as people began to inhabit and live out these alternative stories, the results went beyond solving problems. Within new stories, people could live out new self-images, new possibilities for relationship, and new futures.<sup>7</sup>

In this new mentality, the self is viewed not as an object with a problem, but as an entity with huge potential and vast horizons. The self, which possesses vast resources for change, is the key. Carmel Flaskas views the wellspring of self as "an ongoing ever-changing manifestation of potentiality."<sup>8</sup> Harlene Anderson stresses the incredibly flexible nature of the self, saying that it is "always engaged in conversational becoming constructed and reconstructed through continuous interactions, through relationships."<sup>9</sup>

Therefore, the goal, rather than merely dealing with the problem at hand, is to assist clients in solidifying a preferred story. A robust, preferred story needs to replace the dominant story which is failing to encapsulate experience, or is unhelpful, unsatisfying, and dead-ended.<sup>10</sup> The process involves externalizing problems, deconstructing old stories, and re-authoring new stories by implementing well-crafted

<sup>5</sup> White and Epston, *Narrative Means*, 14.

<sup>6</sup> John Winslade and Alison Cotter, "Moving from Problem Solving to Narrative Approaches in Mediation," in Monk, *Narrative Therapy*, 253-254.

<sup>7</sup> White and Epston, *Narrative Means*, 16.

<sup>8</sup> Carmel Flaskas, "Limits and Possibilities of the Postmodern Narrative Self," *Australian and New Zealand Journal of Family Therapy* 20, no. 1 (1999): 21.

<sup>9</sup> Harlene Anderson, *Conversation, Language, and Possibilities: A Postmodern Approach to Therapy* (New York: Basic Books, 1997), 216, in Flaskas, "Postmodern Narrative Self," 22.

<sup>10</sup> White and Epston, *Narrative Means*, 14.

questions. These questions open up space to create alternate stories. The acceptable result of therapy, according to White, is the “identification or generation of alternate stories that enable them [the clients] to perform new meanings, bringing them desired possibilities.”<sup>11</sup>

### **History: Postmodern Roots**

Narrative therapy has already garnered great influence. Since the end of the eighties both the interest in, and the influence of, narrative therapy has rapidly progressed. Paolo Bertrando explains that manuscripts on this approach have represented the largest group of submissions to his journal.<sup>12</sup> As the “systemic vision replaced the previous psychoanalytical orthodoxy,”<sup>13</sup> so now narrative therapy is gaining ground as the new paradigm which “represents a fundamentally new direction in the therapeutic world and is the third wave.”<sup>14</sup> However, the evaluation of narrative therapy’s effectiveness is still in its infancy. The difficulty in evaluation is intensified by the fact that the entire system is inconsistent with qualitative empirical research methods. Yet even as its effectiveness remains unclear, it continues to grow.

Numerous influences led to the development of narrative therapy. Anthropologist and psychologist Gregory Bateson provided kindling with his views on the subjective nature of reality, as well as with the idea that people do what they do because they are constrained from doing otherwise. The “otherwise” was eventually taken to mean stories that were stifled by familial and cultural discourses.<sup>15</sup> The Milan team also began

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<sup>11</sup> Ibid., 15.

<sup>12</sup> Paolo Bertrando, “Text and Context: Narrative, Postmodern and Cybernetics,” *Journal of Family Therapy* 22, no. 1 (2000): 83.

<sup>13</sup> Ibid., 84.

<sup>14</sup> Bill O’Hanlon, “The Third Wave,” *Family Therapy Networker* 18 (1994): 19-29, in “Review of Narrative Therapy: Research and Utility,” Mary Kleist Etchison, *Family Journal* 8, no. 1 (January 2000): 61.

<sup>15</sup> Alan Parry and Robert E. Doan, *Story Re-Visions* (New York: Guilford, 1994), 17. Here you will find an analysis of Gregory Bateson’s influence.



applying Bateson's ideas, and, instead of looking for patterns of behavior, began focusing on meaning and the premise of "myth" as a shaper of the family.<sup>16</sup> By the mid-seventies, the social sciences had also moved toward a focus on meaning where "culture itself could be treated as 'text.'"<sup>17</sup> Ethnographer Edward Bruner, who showed how people develop stories as a way of understanding and making sense of experiences, also influenced the rise of narrative therapy.<sup>18</sup> Even as far back as 40 years ago, George Kelly initiated clinical constructivism and devised techniques like "self-characterization procedure" to help clients articulate the thematic substructure of their life stories.<sup>19</sup> Second order cybernetics also had an influence on the formation of narrative. The first order cybernetic model encouraged therapists to view people as machines, but it was eventually recognized that such structure models oversimplified life's interactions, and could not capture the shifts and changes inherent in living organisms.<sup>20</sup> In second order cybernetics, the issue of the therapist entering into the family system was positively addressed, and words like "co-evolution" and "co-creation" emerged.<sup>21</sup> Probably the strongest philosophical influence on narrative therapy has come from postmodern French philosopher Michel Foucault, and particularly from his equation of power and knowledge.<sup>22</sup>

The first step in narrative therapy is to begin embracing the postmodern experience of many selves—that is, the belief that each person has a huge range of self-

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<sup>16</sup> Jill Freedman and Gene Combs, *Narrative Therapy: The Social Construction of Preferred Realities* (New York: W.W. Norton, 1996), 5.

<sup>17</sup> Jerome Bruner, *Actual Minds / Possible Worlds* (Cambridge, Mass.: Harvard University Press, 1986), 8, in Freedman and Combs, *Preferred Realities*, 16.

<sup>18</sup> Monk, "How Narrative Therapy Works," 7.

<sup>19</sup> Robert A. Neimeyer and Jonathan D. Raskin, eds., *Constructions of Disorder* (Washington, D.C.: American Psychological Association, 2000), 210-211.

<sup>20</sup> Freedman and Combs, *Preferred Realities*, 3.

<sup>21</sup> *Ibid.*, 3.

<sup>22</sup> White and Epston, *Narrative Means*, 1.

definitions available. In other family systems therapies, Steven de Shazer's solution-focused therapy also has postmodern characteristics, but is more late-modern in nature, whereas narrative therapy flows clearly out of the postmodern waters.<sup>23</sup> Narrative therapy initiated the entrance of family systems therapy into the postmodern realm.<sup>24</sup>

Narrative has invaded therapeutic models with an "attitude of modesty and irony in the face of a growing realization that master plans and techniques are no longer so effective in finding a fit for the incommensurabilities of the human situation."<sup>25</sup> Along with the relativism of postmodernism comes the fluidity and evolving nature of narrative definitions. The idea that one's view of reality is only a limited slice of the whole picture provides the basis for establishing new stories. That "any statement that postulates meaning is interpretive,"<sup>26</sup> has been widely accepted, and this is the basis for opening up life experiences to new interpretations.

Thus, each person is deemed to have the capacity to author reality, for reality is but a construction of individuals within a constructed society. In the words of Paolo Bertrando, "Reality must be considered as a social construction, i.e. realities are but the conversations we have about them, and therefore all views are a consequence of language: every theory and every system of ideas is merely a narrative."<sup>27</sup>

The obvious fruit of such a perspective is doubt regarding the objectivity of truth. Alan Parry explains that when we say something is "true," we are merely conveying that

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<sup>23</sup> Parry and Doan, *Story Re-Visions*, 18.

<sup>24</sup> *Ibid.*, 17.

<sup>25</sup> *Ibid.*, 18.

<sup>26</sup> White and Epston, *Narrative Means*, 5.

<sup>27</sup> Bertrando, "Text and Context," 86.

“a significant community considers it to be true”; therefore, “Any definition of the Real is but an old story that is no longer questioned.”<sup>28</sup>

The skepticism of narrative therapy in regard to absolutes can be found in its postmodern roots. Postmodernism seeks to be honest in admitting that there are limits to humankind’s ability to measure and describe the universe. Postmodernism also doubts the possibility that there is any way to be completely objective in determining what is absolute, if there even is such a definition. The obvious outcome is a suspicious attitude toward the sciences:

Postmodern therapies operate from the premise that all knowledge, including “scientific knowledge,” is *perspectival*, rather than assuming that professionals have access to “objective truth” ...As seen through a narrative lens, therapists and their scientific theories of personality are immersed in predominant cultural influences and ideologies; thus, their knowledge and solutions for mental health are as biased and subjective as those of their clients.<sup>29</sup>

For generations, science has been the critic, but in the postmodern mind, science is now under criticism. For science is seen as seeking to promote an agenda, and the agenda soils the results of the study. B. Latour and S. Woolgar argue that science is not really scientific at all, for “Scientific activity is not ‘about nature.’ It is a fierce fight to construct reality. The laboratory is the workplace and the set of productive forces, which makes construction possible.”<sup>30</sup>

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<sup>28</sup> Craig Smith and David Nylund, *Narrative Therapies with Children and Adolescents* (New York: Guilford, 1997), 5.

<sup>29</sup> Smith and Nylund, *Narrative Therapies*, 7.

<sup>30</sup> B. Latour and S. Woolgar, “Laboratory Life: The Social Construction of Scientific Facts,” (Beverly Hills, Calif.: Sage, 1979), 240, in David Epston, “Internalizing Discourses Versus Externalizing Discourses,” in *Therapeutic Conversations*, ed. Stephen Gilligan and Reese Price (New York: W.W. Norton, 1993), 162.

Once the world realizes that science is not objective, it becomes a place free from the grand narratives, a place where “personal narratives essentially stand alone as the means by which we pull together the text of our own lives, as well as the ‘intertextual’ overlappings of those lives that enter ours. Although this may all be frightening without the legitimating guidance of the grand narratives, it is also a liberating possibility.”<sup>31</sup>

Such “outlandish” perspectives have not left narrative therapy without critics. Some are bold in their challenges of this seemingly heretical orientation. Pittman attacks the logic with this harsh criticism:

Postmodernism entered family therapy in the form of constructivism, espousing that reality is in the eye of the beholder, and that it doesn’t matter what people do, only what story they tell about it. What a breakthrough! People don’t have to change what they do! They can just use different words instead!<sup>32</sup>

However, defenders of narrative therapy offer stimulating points for thought, as well. Bruner says that this world view “does not lead to an ‘anything goes.’ It may lead to an unpacking of presuppositions, the better to explore one’s commitments.”<sup>33</sup> Even postmodern philosopher Richard Rorty gives a lighter view on the implications of this thinking when he says, “The repudiation of the traditional logocentric image of the human being as Knower does not seem to us to entail that we face an abyss, but merely that we face a range of choices.”<sup>34</sup> It is also remarkable that postmodern greats like Jean-Francois Lyotard and Jacques Derrida do not deny the existence of some sort of reality—they merely encourage systematic doubt about one’s premises and theories.<sup>35</sup>

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<sup>31</sup> Parry and Doan, *Story Re-Visions*, 25.

<sup>32</sup> Frank Pittman, “It’s Not My Fault,” *Family Therapy Networker* (January-February 1992): 58, in Epston, “Discourses,” in Gilligan and Price, *Therapeutic Conversations*, 232.

<sup>33</sup> Jerome Bruner, *Acts of Meaning* (Cambridge: Harvard University Press, 1990), 27, in Freedman and Combs, *Preferred Realities*, 21.

<sup>34</sup> Richard Rorty, *Essays on Heidegger and Others* (New York: Cambridge Press, 1991), 132, in Freedman and Combs, *Preferred Realities*, 21.

<sup>35</sup> Bertrando, “Text and Context,” 93.

The narrative therapist prefers to see himself/herself – as the compassionate alternative to the “knowing professional” who seeks “disinterested knowledge” through “detached, disengaged objectivity.” Instead, narrative therapists prefer a collaborative model, committed to co-creating with the client.<sup>36</sup> Jill Freedman and Gene Combs abhor the method that “regard[s] them as objects, thus inviting them into a relationship in which they are the passive, powerless recipients of our knowledge and expertise.”<sup>37</sup>

Narrative therapy is thus far from pessimistic, as it seeks to assist in opening up new and positive stories in peoples’ lives. Therapy may be likened to a journey- a process in which the therapist assists the client toward a preferred future. Therapy can even be compared to process of immigration. White elaborates on this theme, comparing it to the process of immigration from an old country to a new one, leaving behind an old identity and transitioning into a new and better one.<sup>38</sup>

### **The Power of Story**

Stories are potent vehicles of meaning and life. In the words of Craig Smith and David Nylund, “Stories can sweep people up in their wake as they gather momentum.”<sup>39</sup> Not only do stories wield power to engage one’s attention, they seem to hold an almost mystical quality, as well. Joseph Campbell, in *The Power of Myth*, speaks of myth being the public dream, and dream being the private myth.<sup>40</sup> Stories also have a capacity to carry people a person along, and unfold in ways one would not anticipate, because they

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<sup>36</sup> Epston, “Discourses,” in Gilligan and Price, *Therapeutic Conversations*, 233-234.

<sup>37</sup> Freedman and Combs, *Preferred Realities*, 21.

<sup>38</sup> Michael White, *Re-Authoring Lives: Interviews and Essays* (Adelaide, Australia: Dulwich Centre, 1995), in *Collaborative Therapy with Multi-Stressed Families*, William C. Madsen (New York: Guilford, 1999), 225.

<sup>39</sup> Smith and Nylund, *Narrative Therapies*, 11.

<sup>40</sup> Joseph Campbell and Bill Moyers, *The Power of Myth* (New York: Doubleday, 1988), 40.

are both “linear” and “instantaneous.”<sup>41</sup> In a way, stories are almost like living creatures in and of themselves. Even the individual words comprising stories seem to possess life. Rubem Alves, in comparing words to wild birds, says: Flying birds are unpredictable like the Wind: one does not know where they come from or where they are going. Whenever they arrive they work havoc on the order which had been carefully written on the text.<sup>42</sup>

In the ordering of life, stories have a critical role. They become the keepers of reality for humanity, individually and collectively, and the words that compose them can carry both life and death. Thus, in considering the power of narrative, it is not difficult to grasp how problems in life might have their roots in problems of story. J.P. Gustafson noted that problematic periods in life are characterized by gaps in a person’s story.<sup>43</sup> D.E. Polkinghorne drew attention to the way in which narratives ‘decompose’ or ‘disintegrate’ when they become unable to unify new or forgotten phenomena.<sup>44</sup> Gaps in a story become a critical issue when considering that “personal stories are not merely a way of telling someone (or oneself) about one’s life; they are the means by which identities may be fashioned.”<sup>45</sup> This is the hope of narrative therapy: to employ the power of story and the retelling of stories in such a way that gaps are filled and reality expanded. This is a continual process, for, as White and Epston say, “every telling or re-telling of a story, through its performance, is a new telling that encapsulates, and expands upon the previous telling.”<sup>46</sup>

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<sup>41</sup> Edward Bruner, “Ethnography as Narrative,” in *The Anthropology of Experience*, ed. V. Turner and E. Bruner (Chicago: University of Illinois Press, 1986), 153, in White and Epston, *Narrative Means*, 3.

<sup>42</sup> Rubem Alves, *The Poet, The Warrior, The Prophet* (London: SCM Press, 1990), 6.

<sup>43</sup> J.P. Gustafson, *Dilemmas of Brief Therapy* (New York: Plenum, 1995), in “Narrative Disruptions in the Construction of the Self,” Robert A. Neimeyer, in Neimeyer and Raskin, *Constructions of Disorder*, 212.

<sup>44</sup> D.E. Polkinghorne, “Narrative and Self-Concept,” *Journal of Narrative and Life History* 1 (1991): 135-153, in Neimeyer and Raskin, *Constructions of Disorder*, 212.

<sup>45</sup> Atheria Androutsopoulou, “Fiction as an Aid to Therapy: A Narrative and Family Rationale for Practice,” *Journal of Family Therapy* 23, no. 3 (August 2001): 283.

<sup>46</sup> White and Epston, *Narrative Means*, 13.

### Assessment/Approach

Narrative therapy is a collaborative therapy. This means, according to White and Epston, that “narrative therapy begins with an attitude of being an appreciative ally of the family who enters their system and works with, not on, them.”<sup>47</sup> Included in this definition are a couple of key components of narrative therapy. First, more than being a technique, narrative is an attitude—an attitude of acceptance and appreciation for the client, as well as an attitude of skepticism toward systems of meaning that may have the client trapped. Therefore, even from the assessment stage, it is crucial to begin entering “appreciatively” into the client’s system. The second idea is that the therapist enters into the system as a team member who avoids “hogging the ball,” ensuring that everyone present might have a part in the process. The therapist acknowledges the importance of each person, then initiates “a process of unearthing dormant competencies, talents, abilities, and resources.”<sup>48</sup> The result of this attitude “tends to produce numerous moments of excitement and vivacity”<sup>49</sup> in therapy.

A collaborative attitude is continually attentive to the issue of power, the influence of persons within the system, and is cautious not to imbalance that power, thus undermining the vital position of the client. Instead of making people “passive, powerless, recipients of our knowledge and expertise,”<sup>50</sup> the goal is to empower people to re-create, or at least, co-create their new realities. Thus, in the words of Jeffrey Zimmerman and Victoria Dickerson, “We want to make transparent our thinking about

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<sup>47</sup> White and Epston, William C. Madsen, *Collaborative Therapy with Multi-Stressed Families* (New York: Guilford, 1999), 48.

<sup>48</sup> Monk, “How Narrative Therapy Works,” 24.

<sup>49</sup> Ibid.

<sup>50</sup> Freedman and Combs, *Preferred Realities*, 21.

our thinking.”<sup>51</sup> Such an approach abolishes the therapist’s role as the holder of knowledge, and thus, power. Instead, the client is generally seen as the holder of his/her own keys to a better future, as the one who possesses special knowledge that must be uncovered. Gerald Monk describes such a positive view toward the client in this way:

The co-creative practices of narrative therapy require a particular ability on the part of the therapist to see the client as a partner with local expertise whose knowledge may, at the beginning of the counseling relationship, be as hidden as the artifacts of a civilization buried in the soil of centuries.<sup>52</sup>

The concepts of shared power and client as expert are somewhat peculiar for many coming to therapy. Often, those seeking help are more acquainted with the doctor/patient model and expect this relationship to be the same. The conversation Jeff Chang had with a young male client is a helpful example of how to shift this expectation to that of a more collaborative relationship:

Jeff: Do you like going to the doctor? (boy shakes head) Well, when you go to the doctor, like if you’ve ever had an operation, do you do anything when you’re getting an operation?

Boy: (thinking me a bit stupid) No, you’re asleep.

Jeff: Right, you cannot do much to help if you’re asleep. You just go there, the doctor cuts you open, and they pull your guts out... and sew you up, and you don’t do anything, just lie there asleep, right? (nods his head). Okay, well what I like to be called is like a coach. Were you ever in sports?

Boy: Tee ball and soccer...

Jeff: So what does a coach do?

Boy: Teach us how to play the game, help us practice...

Jeff: Right. What about if you lost really bad, 37 to 1, and you were really sad and wanted to give up?

Boy: He would say, it’s not so bad, cheer up, you can do it.

Jeff: Right. So if you have a really good coach, but the players don’t try, will you win the game?

Boy: No.

Jeff: And if you have players that try really hard, but don’t get shown properly by the coach how to play the game, is that good? Will that be a good team? (shakes his head) And sometimes the coach can see things you can’t see from where you are.

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<sup>51</sup> Jeffrey L. Zimmerman and Victoria C. Dickerson, *If Problems Talked: Narrative Therapy in Action* (New York: Guilford, 1996), 43.

<sup>52</sup> Monk, “How Narrative Therapy Works,” 24.



Boy: And sometimes I can see things the coach doesn't see!

Jeff: Right. So if we work together—I'll be the coach and you can be the player, we should be able to help you with your Temper. Deal?

Boy: Deal! (we shake hands)<sup>53</sup>

The creation of a light, even fun, atmosphere is particularly important for children. Children may feel threatened in a discussion with a group of adults, and this feeling is exacerbated when facing a power figure like a therapist or minister. Jennifer Freeman, David Epston, and Dean Lobovits observed that such "serious discussion and methodical problem-solving may impose on children's communication, shutting out their voices, inhibiting their special abilities, knowledges, and creative resources."<sup>54</sup> Children also have the ability to bring unique resources to the therapy process, particularly in their honesty and creative imaginations. Unfortunately, since children are more malleable and easily overrun, their gifts may be stifled. A collaborative approach, however, is careful to create space for everyone.

In this collaborative approach, the traditional stance of authoritative "knowing" is viewed as unproductive to the client and, ultimately, as the source of disempowering. The use of power, warn the proponents of narrative therapy, can be detrimental when wielded unwisely. Wendy Drewery, John Winslade, and Gerald Monk speak of the dominant doctor/patient model, which is pervasive in the world of counseling, as a model which encourages a negative role for the client:

Authoritative diagnosis maintains expert power and thereby adds authority to the intervention that follows on the diagnosis. Recipients of medical care are traditionally thought of as patients, and it is no accident that the word *patient*

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<sup>53</sup> Jeff Chang, "Collaborative Therapies with Young Children and Their Families: Developmental, Pragmatic, and Procedural Issues," *Journal of Systemic Therapies* 18, no. 2 (1999): 47-48.

<sup>54</sup> Jennifer Freeman, David Epston, and Dean Lobovits, *Playful Approaches to Serious Problems: Narrative Therapy with Children and Their Families* (New York: W.W. Norton, 1997), 3.

derives from a term that invokes both suffering and passivity or that the role of doctor invokes so much power.<sup>55</sup>

An attitude that is helpful in enhancing a collaborative environment is what H. Anderson and H. Goolishian term a stance of “not knowing,” where we are “always moving toward what is not yet known.”<sup>56</sup> In this “deliberate ignorance,”<sup>57</sup> as Lynn Hoffman calls it, the therapist seeks to put aside personal interpretations and understand the meaning of people’s stories for *them*. Freedman and Combs suggest consciously avoiding expert status:

This means turning our backs on “expert” filters: not listening for chief complaints; not “gathering” the pertinent-to-us-as-experts bits of diagnostic information interspersed in their stories; not hearing their anecdotes as matrices within which resources are embedded; not listening for surface hints about what the core problem “really” is; and not comparing the selves they portray in their stories to normative standards.”<sup>58</sup>

Bertrando, however, argues that maintaining a “not knowing” stance is likely impossible, that interpretation and judgment are inevitable, and that such an attitude is more wishful thinking than possibility.<sup>59</sup> Certainly, to ignore one’s training and personal views seems an impossibility. Although one may not be able to eradicate “knowing,” the effort to do so may bring about a greater balance of power in the therapeutic process. After all, experts tend to find the very things which they, as experts, have been trained to find. Pathologists will likely find pathology, and thus may only serve to make clients’ pain more vivid and oppressive.

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<sup>55</sup> Wendy Drewery, John Winslade, and Gerald Monk, “Resisting the Dominating Story: Toward a Deeper Understanding of Narrative Therapy,” in Neimeyer and Raskin, *Constructions of Disorder*, 250.

<sup>56</sup> H. Anderson and H. Goolishian, “Beyond Cybernetics: Comments on Atkinson and Heath’s ‘Further thoughts on Second-Order Family Therapy,’” *Family Process* 29 (1990): 159, in Freedman and Combs, *Preferred Realities*, 44.

<sup>57</sup> Lynn Hoffman, “A Reflexive Stance For Family Therapy,” in *Therapy as a Social Construction*, ed. S. McNamee and K. Gergen (Thousand Oaks, Calif.: Sage, 1992), in Monk, “How Narrative Therapy Works,” 25.

<sup>58</sup> Freedman and Combs, *Preferred Realities*, 44.

<sup>59</sup> Bertrando, “Text and Context,” 92.

A “not knowing” stance will also be characterized by an attitude of curiosity. Besides the fun and playfulness that curiosity can bring, it can open space in the discussion for greater breadth and depth. Curiosity comes from believing that each person’s story is very unique, and that the differences which make it unique are worthy of being appreciated and celebrated. This “puzzling together posture” means that the therapist works at “facilitating a safe, exploratory therapeutic environment where diverse, nonpathological, alternative perspectives and stories can be entertained, rather than as expertly providing clients with authoritative, complete, or definitive responses.”<sup>60</sup>

### **Deconstruction: Making Old Stories Dubious**

The first major stage in re-writing life narratives is that of deconstruction. White explains:

Deconstruction has to do with procedures that subvert taken-for-granted realities and practices: those so-called “truths” that are split off from the conditions and the context of their production; those disembodied ways of speaking that hide their biases and prejudices; and those familiar practices of self and relationship that are subjugating of persons’ lives.<sup>61</sup>

In other words, deconstruction is the dismantling of “cultural discourses that sustain oppression and confer dysfunctional identities,”<sup>62</sup> and of the situations in which “what we are doing doesn’t actually fit what we prefer.”<sup>63</sup>

The process of narrative therapy has a similar structure to that of ritual. Ritual, in the view informed by Evan Imber-Black, Joseph Campbell, Sam Keen, and Robert Bly, is composed of three stages: the “separation phase,” the “liminal or betwixt and between

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<sup>60</sup> Smith and Nylund, *Narrative Therapies*, 4.

<sup>61</sup> Michael White, “Deconstruction and Therapy,” in *Therapeutic Conversations*, ed. Stephen Gilligan and Reese Price (New York: W.W. Norton, 1993), 34.

<sup>62</sup> Neimeyer and Raskin, *Constructions of Disorder*, 214.

<sup>63</sup> Zimmerman and Dickerson, *If Problems Talked*, 61.

phase,” and the “reincorporation phase.”<sup>64</sup> Deconstruction in narrative is the process of separating from the old condition and preparing to enter something new. It is getting away from the Popeye mentality of “I yam what I yam” and getting to a place where one can begin to see that there are many choices. This involves a conversation in which the client begins to question and doubt his/her own connection to the problem and his/her version of reality. It is, as Jay Efran and Paul Cook observe:

A conversation that expands clients’ options beyond the limits established by their ordinary social affiliations... highlights the reifications, contradictions, hypocrisies, and paradoxes imbedded in their clients’ stories...an opportunity to sort through the implications of people’s semantic falsehoods.<sup>65</sup>

The conversation is centered around questions in an environment where “a question is as good as the waves it generates.”<sup>66</sup> White and Epston explain, plain and simple, that the narrative approach is “achieved primarily, although not exclusively, through a process of questioning.”<sup>67</sup> Questions, in lieu of statements, advice, or interpretations, are central. These questions are not designed to divulge information that becomes fodder for analysis. Rather, questions are intended to generate experiences that are therapeutic in and of themselves. Perhaps the most basic questions are, What is my story? and Who wrote it? The principle deconstructive question is likely, Do you want to defeat this problem? In answering affirmatively, the client is unified with the therapist. By this answer, the client is also saying no to the problem, and its very hold on his/her life is diminished.<sup>68</sup>

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<sup>64</sup> Parry and Doan, *Story Re-Visions*, 61.

<sup>65</sup> Jay S. Efran and Paul F. Cook, “Linguistic Ambiguity as a Diagnostic Tool,” in Neimeyer and Raskin, *Constructions of Disorder*, 140.

<sup>66</sup> Sluzki, quoted by Salvador Minuchin, “Retelling, Reimagining, and Re-Searching: A Continuing Conversation,” *Journal of Marital and Family Therapy* 25, no. 1 (1999): 9.

<sup>67</sup> White and Epston, *Narrative Means*, 17.

<sup>68</sup> Monk, “How Narrative Therapy Works,” 15.

## Externalizing: The Person is Not the Problem

An important part of the initial deconstruction phase is known as externalization. This is where the problem is reckoned as separate from the person. Epston captures the centrality of externalization to narrative therapy:

If I were to restrict myself to only one aspect of White's work that I have taken over, it would be that of "externalizing the problem." This is summarized by his maxim: "The person isn't the problem; the problem is the problem." This provided a rationale and practice to position myself in therapy, that is, to be on everyone's side at the same time and to act with commitment and compassion against the "problem," whatever the problem might be. It freed me from the constraints of some of the prevailing practices that I found distanced me from the family and reduced my fervor.<sup>69</sup>

This is a revolutionary stance that flies in the face of the entire psychotherapeutic approach—that approach wherein “the problem is most often described as something ‘in’ the other person or something the other is doing *because* of something ‘in’ him or her (a character flaw)...”<sup>70</sup> Externalizing the problem, taking it outside of the person, allows the person to come out from under the microscope. Instead of scrutinizing the client, the therapist and client together scrutinize the “thing” that is plaguing him/her. Of course, “the discourse of mental disorders” which “invites therapists into patterns of stigmatizing and blaming clients, desecrating traditions, deteriorating relationships and disempowering people,”<sup>71</sup> is considered highly damaging.

Madsen writes of a family services program that lacks workers trained in therapy, but nonetheless has an amazingly high degree of success. Louise, one of the counselors in the program, comments:

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<sup>69</sup> David Epston, *Collected Papers* (Adelaide: Dulwich Centre, 1989), 26, in “Discourses,” in Gilligan and Price, *Therapeutic Conversations*, 161-162.

<sup>70</sup> Zimmerman and Dickerson, *If Problems Talked*, 48.

<sup>71</sup> Kenneth J. Gergen and Sheila McNamee, “From Disordering Discourse to Transformative Dialogue,” in Neimeyer and Raskin, *Constructions of Disorder*, 333.

To me pathology is an attacking position. I think to pathologize is to attack... We don't pathologize, but we don't ignore problems either... Our assumption is there's an enormous amount of pain here and we want to go in and as much as we can alleviate some of it or at least have a healthy respect for it without creating more pain.<sup>72</sup>

Not surprisingly, proponents of narrative therapy are somewhat skeptical about the obvious assumptions within the whole categorization of pathologies in the DSM IV.<sup>73</sup> Some view the categorization system as part of the machine of exploitation. Herb Kutchins and Stuart Kirk concluded that "for drug companies, the unlabeled masses are a vast untapped market, the virgin Alaskan oil field of mental disorder."<sup>74</sup> Such labeling also has a potentially negative effect on a young life. According to Jennifer Freeman, "When a therapist listens to, accepts, and then furthers the investigation of a pathological description of a child, the child's identity may suffer."<sup>75</sup>

The chief aim of externalization is to stay clear of "self-attack, recrimination, blame, and judgment, and attitudes which work against positive outcome."<sup>76</sup> Even more than being a method or technical operation, externalization is the language of a particular attitude—the attitude of acceptance. According to S. Roth and D. Epston, "This language shows, invites, and evokes generative and respectful ways of thinking about and being with people struggling to develop the kinds of relationships they would prefer to have with the problems that discomfort them."<sup>77</sup> Epston modeled such an example while counseling a boy suffering from a habitual and life threatening problem with vomiting.

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<sup>72</sup> Madsen, *Collaborative Therapy*, 19-20.

<sup>73</sup> Thomas J. Johnson, et. al., "Constructing and Deconstructing Transitive Diagnosis," in Neimeyer and Raskin, *Constructions of Disorder*, 145.

<sup>74</sup> Herb Kutchins and Stuart Kirk, *Making Us Crazy: The Psychiatric Bible and the Creation of Mental Disorders* (New York: Free Press, 1997), in Gergen and McNamee, "From Disordering," in Neimeyer and Raskin, *Constructions of Disorder*, 342.

<sup>75</sup> Freeman, Epston, and Lobovits, *Playful Approaches*, 9.

<sup>76</sup> Monk, "How Narrative Therapy Works," 6.

<sup>77</sup> S. Roth and D. Epston, "Consulting the Problem About the Problematic Relationship," in *Constructive Therapies*, ed. M Hoyt (New York: Guilford, 1996), 149, in Freeman, Epston, and Lobovits, *Playful Approaches*, 11.

Epston asked a question that captured the spirit of differentiation: “Do you mind if I like you a lot but don’t like your problem at all?” The boy’s response was “Nope.”<sup>78</sup> As mentioned before, questions are central to narrative, and the language of the questions reveals the difference in outlook.

The following are examples of typical questions asked during the process:

Externalizing Questions:

What would you call the problem that is most affecting you?

What’s your main experience when this problem is around? What are you noticing?

Deconstructing Questions:

When did the problem make an appearance in your life? How did it take over?

How does the problem bolster its position?<sup>79</sup>

Notice also the externalizing aspect of the following questions in contrast to their psychoanalytical counterparts:

Psychoanalytical:

How did you become sad?

Externalizing:

What made you vulnerable to sadness, so that it was able to dominate you?

Psychoanalytical:

What are you most sad about?

Externalizing:

In what contexts is the sadness most likely to take over?

Psychoanalytical:

What kinds of things happen that typically lead to your being sad?

Externalizing:

What kinds of things happen that typically lead to sadness taking over?<sup>80</sup>

Mapping: Charting the Territory of a Problem

These questions address another vital aspect to of deconstruction, namely, mapping. Mapping allows one to realize how much his/her life has been dominated by

<sup>78</sup> Freeman, Epston, and Lobovits, *Playful Approaches*, 27.

<sup>79</sup> Adjusted from Neimeyer and Raskin, *Constructions of Disorder*, 303-305.

<sup>80</sup> Freedman and Combs, *Preferred Realities*, 49-50.

the problem and how little space is left for the preferred life. This can greatly enlighten a client because “people inadvertently contribute to the ‘survival’ and ‘career’ of the problem.”<sup>81</sup> Mapping permits a person to see what is keeping the problem alive and well, and thus, what is preventing a new story from being written. Mapping is, metaphorically, like taking a “spy mission” into enemy territory to gain vital and advantageous information.<sup>82</sup>

In mapping, as in externalizing, the process is carried out through asking and answering questions. Typical mapping questions might include: What is problematic here? How does it show itself? What does it feel like to be under this problem? Who has been influenced by it? How?

#### Objectifying: A Problem Takes On Its Own Flesh and Blood

A unique practice in narrative therapy, and the key to externalization, is objectifying the problem. Objectifying usually includes giving the problem a specific name, which is akin to naming an enemy. Naming helps to target the problem, although Zimmerman stresses that speaking objectively of the problem is even more important than naming it.<sup>83</sup> For some people, “naming” may be half the battle, for, as magician Harry Lorayne says, “most problems precisely defined are already partially solved.”<sup>84</sup> Giving problems names seems akin to the positive practice of using symbol and metaphor to avert personal identification with the problem. Children may experience particular benefit in naming, for children tend to experience problems as parts of themselves.<sup>85</sup>

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<sup>81</sup> White and Epston, *Narrative Means*, 3.

<sup>82</sup> Parry and Doan, *Story Re-Visions*, 55

<sup>83</sup> Zimmerman and Dickerson, *If Problems Talked*, 49.

<sup>84</sup> Harry Lorayne, in D. Millman, *The Inner Athlete*, (1994), in Efran and Cook, “Linguistic Ambiguity,” in Neimeyer and Raskin, *Constructions of Disorder*, 141.

<sup>85</sup> Chang, “Collaborative Therapies,” 50.



The types of problems in clients' lives that can be named are legion. There are deficits in behavior, unfavorable relationships, conflicts, hostilities, misunderstandings, and despair. Whatever affects the people, patterns, or relationships has a potential name.<sup>86</sup> Naming may also help unmask the "cultural truths"<sup>87</sup> and the "toxic effects of cultural narratives"<sup>88</sup> that suck life out of a family, challenging or endangering its true call. The progression of deconstruction is simple: naming, knowing, and conquering.

Objectification and naming result in an interesting personification of the problem. The problem seems to evolve into another "being" which has come uninvited into the life or home. Zimmerman and Dickerson playfully explore this possibility in *If Problems Talked: Narrative Therapy in Action*.<sup>89</sup> In this work, the authors invent the thinking and speech of the problems, entering into dialogue with them, as well. The following are examples of the self-talk the problems themselves divulge. The name of the problem in this case is "Rift," referring to the fracture plaguing a family with a teenager. Rift comes alive through the creative dramatization of its speech:

I am very powerful. I don't know, though, what I think about being called "Rift."

I put looks of concern and worry on the faces of the parents, and a scowl on the young person's face. Often I have a teenager refusing to come into the room—staying in the car or yelling...I can even jump over phone lines, putting anger in the parent's voice, or tears and frustration.

They think they can get me this way, but I outwit them by masking my effects and getting therapist and clients alike to think that I only have one or two people under my control—certainly not the whole family. I can get each person in the family to develop stories about the others that make them 'bad.' Then I can make a case for separating and isolating, rather than for the family members' working together.

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<sup>86</sup> Zimmerman and Dickerson, *If Problems Talked*, 52.

<sup>87</sup> Ibid., 42.

<sup>88</sup> Richard C. Schwartz, "Narrative Therapy Expands and Contracts Family Therapy's Horizons," *Journal of Mental and Family Therapy* 25, no.2 (April 1999): 264.

<sup>89</sup> Jeffrey L. Zimmerman and Victoria C. Dickerson, *If Problems Talked: Narrative Therapy in Action* (New York: Guilford, 1996).

As I've said earlier, I love this way of thinking, confusing me with the person. It lets me hide and be powerful.<sup>90</sup>

By the magic of naming and personifying, a problem can finally be seen as a villain with vulnerabilities. No longer is it shrouded in mystery, but rather, it is a foe that can be conquered. A case in point is the legendary story of Tom and "Sneaky Poo," an oft-referred to example in narrative therapy. Tom, a boy plagued with failure in the area of potty training, would typically have been labeled with some pathology. However, he conquered his problem by facing the fact that "Sneaky Poo ha[d] been stinking up [his] pants and life." He rose to meet the challenge by believing that he could "outsmart Sneaky Poo."<sup>91</sup>

The overriding goal of the therapist in the stage of deconstruction is to slightly shift or loosen the hold of an old story. Loosening the problem's grip is what White calls the "unique outcome" and Monk calls the "sparkling moment."<sup>92</sup> Every inch that the dominant story loses becomes acreage on which to build a new narrative. When deconstruction is successful, there are many perks for the family:

- Decrease in conflict between people
- Reduction in the sense of failure
- Uniting of people against problems
- Opening of space for reclaiming lives
- Liberation of people to view problems in new ways<sup>93</sup>

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<sup>90</sup> Zimmerman and Dickerson, *If Problems Talked*, 44-49. This book is a creative masterpiece in imagining the viewpoint of a problem, a veritable narrative version of *The Screwtape Letters* of C. S. Lewis. The authors even select age appropriate language for a group of little demons, who are discouraged about their failure in controlling children, by having them lament, "We're so depressed!"

<sup>91</sup> Michael White's client in Freeman, Epston, and Lobovits, *Playful Approaches*, 9.

<sup>92</sup> Monk, "How Narrative Therapy Works," 13.

<sup>93</sup> Adapted from Parry and Doan, *Story Re-Visions*, 53, and White and Epston, *Narrative Means*, 39. Each author gives a similar, but slightly different list. This list seeks to join and abbreviate both.

## Re-Authoring

What made the difference for the Scarecrow, Tinman, and Lion of Oz? New stories made the difference—stories that radically changed their identities and lives. The three characters' lives were so revolutionized that they were handed the throne of the Emerald City. Of course, the Wizard of Oz is only a storybook, but peculiarly, peoples' lives in the real world are often quite similar to storybooks. Just like any storybook goes through many revisions, so life stories can be revised. Freedman writes that "the key to this therapy is that in any life there are always more events that don't get 'storied' than there are ones that do—even the longest and most complex autobiography leaves out more than it includes."<sup>94</sup> It is through finding these "un-storied" details that lives can be "re-authored." In the words of Monk, re-authoring is merely a "re-description of self."<sup>95</sup> The process of re-authoring can continue for a lifetime.

The narrative therapist operates under the belief that "countless lives inhabit us,"<sup>96</sup> that there are "subuniverses of meaning"<sup>97</sup> to be discovered, and that each person already possesses the experiences that are problem defeating.<sup>98</sup> Thus, the therapist carefully searches for these overlooked experiences, pulls them from the dust, and helps breathe new life into them. Thomas Carlson speaks of "rescuing events" that contradict the problem-saturated story.<sup>99</sup>

Monk uses two potent illustrations for this process. One is that of stringing pearls. The pearls are exceptions to the dominant story and it takes care to string them together

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<sup>94</sup> Freedman and Combs, *Preferred Realities*, 32.

<sup>95</sup> Monk, "How Narrative Therapy Works," 20.

<sup>96</sup> Neimeyer and Raskin, *Constructions of Disorder*, 207.

<sup>97</sup> P. Berger and T. Luckmann, *The Social Construction of Reality* (New York: Doubleday, 1966), 86, in Freedman and Combs, *Preferred Realities*, 36.

<sup>98</sup> Zimmerman and Dickerson, *If Problems Talked*, 60.

<sup>99</sup> Thomas D. Carlson and Martin J. Erickson, "Re-Authoring Spiritual Narratives: God in Persons' Relational Identity Stories," *Journal of Systemic Therapies* 19, no. 2 (2000): 74.

one by one together. The other illustration is that of building a fire by focusing on positively lived events (the kindling, twigs, and logs) and piling them carefully at the right times, taking care not to snuff out the flame.<sup>100</sup>

As the therapist helps the client determine what experiences have been silenced or marginalized, questions are once again at the center of the process. Some questions that aid in finding “pearls” might be:

Did you struggle with the problem this week? Did you win even a little?  
Are there some relationships which the problem has not invaded?<sup>101</sup>

Upon finding pearls, one can begin to string them by using other questions of curiosity:

This is a mystery to me. You are getting around the problem.  
How could you do that? What’s your secret?

Instead of focusing merely on the absence of the problem, one may use questions to focus on the presence of strengths:

What would you like me to know about you first?  
What do you want to be known for?  
What do you enjoy most?  
What is something you are proud of?<sup>102</sup>

As experiences are unpacked and viewed from a different perspective, pearl after pearl is strung, and hopefully knotted in-between to prevent unraveling. These knots are the solidifying quality of making a tight story with no gaps. Freeman writes of the importance of thickening the counter plot, where “characters, their intentions, and their circumstances are as well developed, colorful, and convincing as the problem’s.”<sup>103</sup> For if the elements are not convincing enough, the story will lack solidity and will forfeit

<sup>100</sup> Monk, “How Narrative Therapy Works,” 16-17.

<sup>101</sup> Adjusted from Neimeyer and Raskin, *Constructions of Disorder*, 303-305.

<sup>102</sup> Adaptations of Freedman and Combs, *Preferred Realities*, Chapter 5 “Questions.”

<sup>103</sup> Freeman, Epston, and Lobovits, *Playful Approaches*, 95.

longevity. The careful therapist will skillfully aid the client in bringing living, breathing flesh to a new reality.

While simultaneously thinning the plot and thickening the counterplot, there is much room for play and creativity. The “miracle question,” namely, If you woke up tomorrow and the problem was gone, what would things look like? The “pretend ‘as if’” exercise, where the client imagines what a new life would be like, may also be implemented. Solidifying the new position may also involve practicing and role playing with elements of the new story, or asking a client to describe how he/she will make the changes—will it occur all at once, or will he/she slowly slip into them? Letter writing has also been used extensively in narrative therapy; vital words are penned and woven in a way that provides an anchor for the new story, so it won’t be forgotten.<sup>104</sup>

Freeman refers to a case of helping a boy thicken his new narrative without rage. She collected an assortment of toys in a pouch and named it his “Temper Tamers Kit.” It contained a spyglass to remind him to be on the look out, a whistle to blow when he saw temper coming, a notebook to record his encounters with temper, and an assortment of other powerful toys.<sup>105</sup> Often, just by telling the story audibly, in a new environment, the client may notice that he/she is already participating in an alternate story or revision. Through this process, the client is empowered, for he/she has a hand in shaping his/her own stories, rather than being shaped by them.

### **Re-Membering**

The final stage in the process of narrative therapy is re-membering, which deals with developing a social setting for the clients that will “assist them in living out

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<sup>104</sup> Extensive examples are available in White and Epston’s seminal work, *Narrative Means to Therapeutic Ends*.

<sup>105</sup> Freeman, Epston, and Lobovits, *Playful Approaches*, 13.

narratives that support the growth and development of these ‘preferred selves.’”<sup>106</sup> The challenge at this stage is that the system an individual or family lives in will resist change. Change is challenging because systems seek to remain cozily stable, and people are well practiced in old narratives. Most narratives have been played out for years, even lifetimes. It is no wonder, then, that increasing the number of “appreciative allies” in the system is crucial. The therapist seeks to help the people involved in the lives of these young people to engage in practices of language that generate stories of learning, success, and competence, rather than stories of deficit, failure, and incompetence.<sup>107</sup>

In “recruiting an audience” that will advocate this new narrative, the first candidates are those most likely to influence the life of the person or family. This may include the deceased, for psychosocial relationships continue their influence even beyond death. In working with the influence of the deceased, imagination will have to be employed, but to find the influencers who are living, the therapist might ask, Who of the people you admire would be least surprised by the change in you? or Who will notice the change first? These people are then brought into the dialogue and informed of the new narrative and its implications. Their understanding and cooperation is of premium importance. At some point, the therapist may even aim to take a client further by asking, If someone who was struggling with your old problem said, “It’s no good. It’s hopeless. The problem is too strong for me!” what would you say? Such questioning moves the client to a new level—not just from victim to survivor, but from victim to consultant. In this way, the formerly powerless gain the role of changing lives by helping spread new narratives.

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<sup>106</sup> Freedman and Combs, *Preferred Realities*, 35.

<sup>107</sup> Smith and Nylund, *Narrative Therapies*, 221.

## CHAPTER 5 INTEGRATION FOR EMPOWERMENT

### **Introduction The Power of Disability**

At the risk of violating academic or scholastic protocol, I venture to make a shift in voice and transition to the viewpoint of first person. The reason for this shift is that the issues surrounding the special needs family are entirely personal; they are a daily life experience, as I have a daughter who is deaf. The sorrow, the frustration, the stress, and the spiritual journey are all paths that were, and are, being traversed. The insights, the depths, and the joys are also an integral part of this life. I believe that my highest qualification in addressing issues related to disability is not in some diploma, or a degree that may result from this document, but in some wisdom gained through having a girl named Sophia. The text included herein is not merely something gleaned from yellowed pages in a dusty library (they were actually quite beautiful libraries and very potent writings), rather, these words have been sustenance for our empowerment.

Gut-wrenching information regarding the issues surrounding disability has plagued me in my research. My heart weeps as I realize realizing the likely fate of most special needs families, in contrast to their possible destiny. My eyes stream when I see that most children not only suffer greatly from their disability, but also from abuse, broken homes, and isolation—often becoming handicapped emotionally, relationally, and spiritually.

The issues surrounding disability contain a vast, potent power to move hearts and spur volition. Yesterday, I tearfully read Alex Pearson's description of a memorable Eucharist:

Last Sunday in church I watched as a father and severely handicapped son came up and the father took the sacramental body and blood of our Lord, and after dipping the former in the latter, proceeded to stuff it into his son's mouth, while his son beamed. I cried; for the first time in a while, it wasn't just my eyes tearing up, but tears ran down my face. I was touched by the beauty, and the happiness, mixed with homesickness...

The symbolic presence of this boy at Eucharist opened for me, enlightening me. The broken boy partaking of the broken body became a reminder of the verse where Jesus broke the bread and said, "This is my body given for you."<sup>1</sup>

Disability gains entrance to "limited accessibility" places in the heart. Coupled with this capacity for entry is the capability that children have to enter into our hearts. We all have, in the words of Stephen Gilligan, "an indestructible tender spot which exists at the core."<sup>2</sup> A child struggling with disability has effective means to touch that spot. The following fairytale captures this capacity:

Princess Eleanor always got whatever she wanted. Every one of her whims was fulfilled by order of her father, the king. Consequently, Eleanor never cried.

One day she said to her father, "I want to see God."

"God? But no one has ever seen God," her father said.

"That is exactly why I want to see Him," Eleanor replied with a smile.

"If that is what you want, that is what you shall get," he told her.

The king asked his chief judge to show God to Eleanor. The judge led Eleanor to the royal library where the Great Book of Law was kept.

"This book contains all the law in the kingdom. It is as good as God," he stated.

Eleanor was not impressed. She stamped her foot and insisted that the book was not God.

Next, the king called on the royal treasurer and asked him to show God to Eleanor.

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<sup>1</sup> Luke 22:19, New International Version.

<sup>2</sup> Stephen Gilligan, *The Courage to Love: Principles and Practices of Self-Relations Psychotherapy* (New York: Norton, 1997), 4, in "Collaborative Therapies with Young Children and Their Families: Developmental, Pragmatic, and Procedural Issues," Jeff Chang, *Journal of Systemic Therapies* 18, no. 2 (1999): 60.



“Very well,” he replied as he led the princess off to the royal treasury.

The treasurer unlocked and swung open the thick iron doors, and showed Eleanor all the glistening gold.

“But I want to see God, not just a pile of gold,” she screeched.

Wondering how to fulfill Eleanor’s wish, the king took a walk, and noticed an old man planting a tree.

“Do you expect to live long enough to enjoy the fruit from that tree, old man?” the king asked.

“No, but I hope my grandchildren will enjoy it, God willing,” he answered.

“God willing?” the king repeated. Then he asked the old man, “Do you know where to find God?”

The old man answered with a question: “Don’t you?”

“I am not sure,” the king replied. “My daughter wants to see God. Could you show God to her?”

The old man agreed. When Eleanor arrived she demanded to see God and threatened the man with all kinds of dire consequences if he did not fulfill his promise.

“Not so fast,” said the old man. “First you must come with me.”

They walked to a ramshackle hut at the far end of town. The old man knocked on the door and told the princess to go in. She pushed the door open. Never before had she seen such poverty. Sitting at table was a little girl dressed in old and ragged clothing. Eleanor ordered the girl to rise in the “presence of the princess.” But the girl was crippled and unable to stand.

Eleanor’s head began to spin as she backed out of the hut and closed the door behind her. Silently, the two returned to the palace. The princess had completely forgotten about herself and her demand to see God.

Seeing this, the old man smiled and said, “Now you are ready.”

He handed the princess a mirror and asked her to look deep inside her soul. For the first time in her life, the princess who never cried had tears rolling down her cheeks. The old man asked her why she was crying.

“All my life I have been selfish and have thought only of myself. I never realized how selfish I was! Do you think it would help if I brought that girl food and warm clothes to wear?” she asked.

The old man put away the mirror and said, “Now you have seen God.”<sup>3</sup>

The phenomenon of this story is not uncommon. The mere presence, or even the “inappropriate” behavior, of those with disability can initiate the meltdown of a cold heart, or even a frigid church. A group with mental disabilities from the L’Arche community was making a pilgrimage to the Canterbury Cathedral at Easter. Suddenly, during the service, they began dancing in the aisles and before the altar. Apparently,

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<sup>3</sup> Adapted from M. Cone, “The Princess Who Wanted to See God,” *Who Knows Ten? Children’s Tales of the Ten Commandments* (New York: Union of American Hebrew Congregations, 1965), in *Flash of Insight: Metaphor and Narrative in Therapy*, Stephen S. Pearce (Boston: Allyn & Bacon, 1996), 157.

never in the history of Canterbury had there been such a display of joy in worship. The Dean of the Cathedral was so deeply moved that he cried. The Archbishop of Canterbury himself was so inspired that, in that great and solemn cathedral in Britain, on the greatest and most solemn of feast days, he rang a bell, much as the Pilgrims to Canterbury have traditionally done.<sup>4</sup>

Disability possesses the potential for immense good. This good is of the variety that comes only through a journey that seems anything but good. Pain becomes a passageway to a much larger and simpler world. In the words of Kahlil Gibran, "Your pain is the breaking of the shell that encloses your understanding."<sup>5</sup> This is part of the gift that special needs families have to offer this world. As the trivial distractions of society are exposed, a perspective of what really matters emerges. When I asked Matthew Pearson what his child and his family have to offer others, his reply was stark and simple: "Our presence."

Presence may be all that is needed, for in the simple act of being, a perplexing and life-changing power is released. The silent world my daughter brought into our family completely revolutionized our view of life. David and Lo-Ann Trembley write about the particular significance of the fruits of the Spirit that are displayed through the lives of several people with disability:

Shy, introverted Minnie greets and takes leave by gently hugging and laying her head on one's shoulder. Minnie doesn't say much, but her actions speak volumes about demonstrating *love*. Phyllis can squawk out only a few recognizable syllables, but she claps her hands with *joy* when she is the first person to recognize a plaque of praying hand as the latest addition to the worship space. Billy was kept in a closet for most of his 23 years. During that time his only

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<sup>4</sup> Attributed to Shearer (1974), in Wolf Wolfensberger, "The Prophetic Voice and Presence of Mentally Retarded People in the World Today," *Journal of Religion, Disability, and Health* 4, no. 2-3 (2001): 27.

<sup>5</sup> Kahlil Gibran in Kathleen Deyer Bolduc, "Embracing Our Brokenness: Poems and Reflections on Disability and the Kingdom," *Journal of Religion, Disability, and Health* 4, no. 4 (2001): 66.

comfort was masturbation. Billy has no speech, but he demonstrates *self-control* as he learns to curb his impulses in a public situation.<sup>6</sup>

### Two Approaches for Empowerment

In empowering special needs families, numerous needs scream for attention. Many parents echo that their greatest need is respite.<sup>7</sup> Certainly this is a valid issue. If family, friends, and church were more present in this ministry, could it purge these people of the ingratitude that possibly fuels a rampant divorce rate, among other things? This document has not touched on the issues of respite, or advocacy, or accessibility—all of which are critically important. Rather, the aim has been focused on how to empower the family as a spiritual entity, an issue that permeates every other aspect of family life. Thayer defines “spiritual” as “conscious of, and relat[ing] to a dimension of power and meaning transcendent to the world of sensory reality.”<sup>8</sup> Thus, the goal has been to give some insight into enabling special needs families to live within this “transcendent power and meaning,” and to live on a level that is beyond, yet intricately tied to this world. This is a difficult task, for “there is no single model for living with a disability, no single way of ‘handling’ or perceiving it.”<sup>9</sup> There is no jello mold or rubber stamp intervention for these families. Each family is unique, and all disabilities are not of the same magnitude.

However, I believe the approaches of spiritual direction and narrative therapy carry weighty potential for empowering families affected by disability. Narrative therapy encourages a family to challenge both its own and society’s perspective of disability, and

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<sup>6</sup> David Trembley and Lo-Ann Trembley, “God in the Oven: About the Demonstration of Faith and Gifts of Persons Who Have Developmental Disabilities,” *Journal of Religion, Disability, and Health* 5, no. 1 (September 2001): 79.

<sup>7</sup> See archives of parents’ inspirational writing at Our Kids website: <http://www.our-kids.org>

<sup>8</sup> Nelson Thayer, *Spirituality and Pastoral Care* (Philadelphia: Fortress Press, 1985), 55, in “Spirituality and Systems Therapy: Partners in Clinical Practice,” Douglas A. Anderson, in *Religion and the Family: When God Helps*, ed. Laurel Arthur Burton (New York: Haworth Pastoral Press, 1992), 89.

<sup>9</sup> Helen Betenbaugh and Marjorie Proctor-Smith, “Disabling the Lie: Prayers of Truth and Transformation,” in *Human Disability and the Service of God: Reassessing Religious Practice*, ed. Nancy L. Eiesland and Don E. Saliers (Nashville, Tenn.: Abingdon, 1998), 287.

it frees its members to live by a different story. Spiritual direction is a channel through which a family can find eternal meaning and divine power, even amidst the struggle. Acquiring a new story, eternal meaning, and divine power can be critical, not just in order for the family to thrive, but even for it to merely survive.

Why were these two approaches selected? In recent years, there has been an incredible rise in the postmodern influence (narrative/social-constructionism), as well as in spiritually focused counseling (akin to spiritual direction).<sup>10</sup> There are those who believe that the surge of these two movements in the field of therapeutic counseling is no mere coincidence.<sup>11</sup> Together, these approaches balance the responsibility for change and empowerment between the realms of humanity and divinity. Yet, while utilizing both perspectives, there may be balance and benefit in allowing them to maintain their distinctiveness.

### Similarities

Both approaches drip with ripeness for today, as they follow an inevitable consequence of our times.<sup>12</sup> Benevolence toward spirituality and antagonism for the scientific view of life pervade much of today's society. The rise of the postmodern worldview has birthed a new openness in the spiritual realm, because "social constructionist theories provide a natural framework for incorporating the religious and spiritual beliefs of clients' lives."<sup>13</sup>

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<sup>10</sup> These two interventions have emerging side by side in numerous places. Dorothy Becvar's choice of chapter titles in *Soul Healing: A Spiritual Orientation in Counseling and Therapy* (New York: Basic Books, 1997) is one example. Chapter titles, back to back, read, "Trusting the Universe" and "Creating Realities."

<sup>11</sup> Thomas D. Carlson and Martin J. Erickson, "Re-Authoring Spiritual Narratives: God in Persons' Relational Identity Stories," *Journal of Systemic Therapies* 19, no. 2 (2000): 66.

<sup>12</sup> Douglas A. Anderson, "Spirituality and Systems Therapy: Partners in Clinical Practice," *Religion and the Family: When God Helps*, ed. Laurel Arthur Burton (New York: Haworth Pastoral Press, 1992), 92.

<sup>13</sup> Carlson and Erickson, "Re-Authoring Spiritual Narratives," 67.

But in what ways are the two approaches similar? Although spiritual direction aspires to reach a new connection and narrative therapy aims at a new story, the outcome of each is a new description of reality. In both approaches, this new reality entails a new call and sense of being. This new call refers to a new view for living life, and this new sense of being is a way of existing.

The beauty of each approach is that it is innately simple. This has particular benefit when dealing with families that include children and those with mental disability. Children love playfulness, creativity, imagination, and stories, which are all components of the process in both. When the approaches are combined, the outcome becomes the re-authoring of a spiritual narrative—developing stories with a theme of God’s love, protection, and purpose. Thus, the meaning of experiences relied upon to support the problem would be transformed to support a new story of God’s love despite disability.

The view of knowledge and power is another similarity. Neither approach views the power as resting in the lap of the helper. Both emphasize a “not knowing” position of discovery. Both seek to agitate a greater reality within the directee/client, a reality wherein life is much larger and more creative than presumed before. Neither approach seeks to merely solve problems, but each seeks to deconstruct the power of the lie, whether spiritual or social, and to find entrance into an existence that transcends this world.

### Differences

The two approaches are also very different, and in this, they seem to complement each other. The human emphasis in narrative therapy helps to correct the tendency of over-spiritualizing problems. It does this by stressing that our inner experiences are

related to meanings derived from past experiences, and from the discourse in which we live. Many issues in life are not merely spiritual. We are beings of many facets, and utilizing an approach in the field of therapeutic counseling helps to answer questions about our diverse makeup.

Spiritual direction, on the other hand, tends to keep in check potential imbalances in the postmodern mindset. Direction keeps a God focus at the center of the dialogue, thereby avoiding the vacuum of a humanist viewpoint. True self is viewed as having ancient and eternal linkings, and Divine power is needed to find strength, hope, and healing. Self is not the master, but rather, is enveloped in the Mystery. Many believe that “the behavioral sciences can only take us to the gateway of meaning, and spirituality is needed to move through it.”<sup>14</sup> An approach that ignores the spiritual obliterates the Divine encounter, and inhibits Relationship with a capital “R.” It is wise to remember that both approaches are different; in spiritual direction, we have a movement from false self to spiritual child, whereas in narrative therapy, we have a movement from cultural discourse to preferred being.

### Special Needs Families and Spiritual Direction

How does spiritual direction benefit the special needs family? Direction provides a special opportunity to deal with two huge barriers. The first is related to connection and the second to meaning. Any family confronted with disability will have to struggle with the perplexity of the existence of both suffering and an omnipotent, benevolent God. Many families get stuck in this struggle and hit a spiritual impasse. Few want be connected to a “hateful God who causes pain” or an “irrelevant God who does not cause

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<sup>14</sup> Source of this quote unfortunately lost.

pain but is powerless against the forces who do.”<sup>15</sup> Special needs families will easily arrive at the conclusion that God is either punishing them (resulting in guilt), or that he is unjustly imposing on them (resulting in bitterness). They become blind to the fact that their lives are filled with many blessings, because their focus is overwhelmingly on the sufferings. This results in feeling unloved, abandoned, or even rejected by God.

The great tragedy of this phenomenon is that the special needs family separates itself from God and flounders in its own strength. Tan reminds us, “Christ should also be the answer for the disabled and their families.”<sup>16</sup> Crudely stated, God is the “metaphysical glue” that holds the family together; the source of love, joy, peace, and everything that a family needs to weather the tumult of disability. Spiritual direction puts the issue of connection to God at the center, not as a secondary consideration, but as the most potent relationship in life.

The second barrier that spiritual direction answers is related to meaning. Without a sense of eternal meaning, a sense that everything is part of an ancient plan and purpose, there is little hope for the family that suffers grave loss or colossal frustration. A spiritual view opens a new horizon of meaning. Families have the opportunity to enter life on another level. Quadriplegic Joni Eareckson Tada says, “I think the most blessed benefit of suffering on this earth is to force us to make eternal decisions.”<sup>17</sup> Eternal decisions, not just day-to-day and keeping-the-head-above-water decisions, are easily postponed. Living with disability can effortlessly become the primary focus of a family. Due to the enormous amounts of attention that must be lavished on a disability, family members become distracted from connecting with God, self, and family.

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<sup>15</sup> Charles Gourgey, “Disability and Destiny,” *Journal of Religion in Disability and Rehabilitation* 2, no. 1 (1995): 76.

<sup>16</sup> Amanda Shao Tan, “The Disabled Christ,” *Transformation* 15, no. 4 (October-December 1998): 9.

<sup>17</sup> Linda Piepenbrink, “Joni Eareckson Tada’s Secret to Joy,” *Virtue* (October-November 1998): 66.

Spiritual direction helps the family to hear not just words, but the Word coming out of one's "forgotten depths."<sup>18</sup> Through this Divine connection, a family may be able to boldly proclaim:

You don't have the slightest inclination of the depth and breadth of the grace of God that I have experienced, the intimate ways in which I have been touched by the Divine, the powerful ways in which I have encountered the *Mysterium tremendens et fascinans*.<sup>19</sup> Like Job, I have had an experience of God that radically changed my way of looking at things. Like Jacob, I have wrestled with God, have persevered until I received God's blessing, and have received a new name.<sup>20</sup>

The members of the Pearson family, who were described in Chapter Two, may be empowered by an advocate that will help them to halt and hear the Voice within—not the voice of a distant god but of the One who is entirely present. As the Pearson's learn to hear the Voice, their turmoil can begin to calm. Though David is encumbered by severe mental disability, it is possible that he has the same capacity as the rest of the family to experience God, to hear his voice, and to savor this calm, as well. The family will benefit in re-discovering that it will only flounder in its own strength, and that God is the ultimate source of energies so desperately needed. The family needs a friend who will help it realize the hope of believing that its suffering is not vain, that there is eternal meaning which will bring blessing, though presently life may be shadowed in a dark mystery.

### Special Needs Families and Narrative Therapy

How does narrative therapy benefit the special needs family? Quite simply, I believe its greatest benefit is in helping to free a family from the perspective of an anemic culture that disdains disability and adores the things that destroy family, such as

<sup>18</sup> Rubem Alves, *The Poet, The Warrior, The Prophet* (London: SCM Press, 1990), 18.

<sup>19</sup> This phrase describes God as a mystery that both attracts with its fascination and terrifies with its tremendous power. Rudolf Otto, *The Idea of the Holy* (London: Oxford University Press, 1950), 12-30.

<sup>20</sup> Helen Betenbaugh, "Disability: A Lived Theology," *Theology Today* 57, no. 2 (July 2000): 209-210.



materialism and the quest for egotistical productivity. The narrative approach gives the family members space to determine whom and how they want to be. This is a critical empowerment for the special needs family that must struggle with the handicapping attitudes, values, and priorities that surround, and often permeate, it. Handicapping attitudes, values, and priorities are statements that infer, "You are incapable. You are insignificant. You are inferior." Though these families must live in a harsh world, with the help of narrative, they can embellish the text of a separate world. Wood gives a good description of two possible worlds that exist on earth:

### "Two Worlds"

For us, there are Two Worlds of Being.  
The first World is the outer world we live in,  
A shell that encases the body, an attitude  
That stifles the mind and pretends  
That money is the measure of worth.

The First World is harsh, though comfortable,  
Alluring, though vain. It is the popular world  
Where everyone longs to be, yet once they arrive,  
They dream of a new direction. In this world,  
Everything costs something and what is free costs more.

The First World is one of wheels and destinations,  
Membership dues and limitations. It is a sanctuary  
For those who desire conformity in all things.  
Here duplicate people wearing duplicate clothes  
Speak a language without meaning, and think thoughts  
Without substance in their form.

The First World is where everyone lives, yet  
No one actually survives. It is an acceptable address  
Where you forfeit all that you are for what  
You will never become and what you are not  
Is what you want those around you to remember.

The First World has power, but no strength.  
It is one of mirrors, but no reflection.  
In this world, there is success, but no mystery.

Goals, but no journey. In this world,  
Boundaries keep ideas from colliding...

[And then]

The Second World is one of joy and curiosity,  
A connecting thread to birds and oceans, plants and animals.  
The Second World is one of children's laughter, women's songs,  
Men's stories, the essence that remains long after the experience  
Has passed on...<sup>21</sup>

At some point, special needs families must make the distinction between the two worlds; otherwise, life is infested with confusion and frustration. Special needs families will not likely survive in the "First World." The futile endeavor to live by those standards will only lead to dissolution of entity and sterility of life; families will tear apart and lives will be shallow. But in the narrative approach, one is emboldened to face the real culprit, a hurtful discourse, and banish it from the home by rewriting the narrative of family life. As space for new stories opens up, stories can take on a new form:

<u>Not stories of</u>	<u>But stories of</u>
Fear	Hope
Anger	Compassion
Guilt	Grace
Loneliness	Communion
Grief	Meaning
Sorrow	Depth
Bewilderment	Vision

The members of the Pearson family, like those of any special needs family, can be empowered by an advocate who helps them identify the existence of more than one world and that they may choose which world to embrace. Choosing one's world is synonymous with finding a new story, one that matches the family's identity and call. This story is not based on the cultural sludge in which the family is immersed, but is based on what is

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<sup>21</sup> Nancy Wood, *Spirit Walker* (New York: Delacorte Press, 1993), 54-55, in *Soul Healing: A Spiritual Orientation in Counseling and Therapy*, Dorothy S. Becvar (New York: Basic Books, 1997), 149-150.

helpful for the family's existence. The Pearsons would benefit from realizing that they are distinct and have no need to compare themselves with others or to have unrealistic expectations for themselves. David cannot be expected to fit into the world—that is not possible—rather, the world, or at least David's own family, will have to embrace him as he is. The Pearson family needs assistance to keep off society's merry-go-round and continue the real journey—this is true empowerment for their survival and fulfillment.

### Final Consideration of Approach

In summary, I propose that the ultimate outcome of these two approaches, when used together, will be a new story and new connection, resulting in a new reality and a new being. I do not believe empowerment is about a strategy or technique. There are no strict blueprints; the spirit of both approaches is deep and wide, and originates in the pre-modern and the postmodern. What is most empowering to the family seems to be an attitude that models and emphasizes a way of being. This view opens the door to many more possible helpers. Madsen was dumbfounded observing this phenomenon in the narrative realm, stating that, "They were not 'technically proficient' therapists. They had neither an articulated conceptual framework nor a set of techniques from which to draw. And yet, they were doing remarkable work with families."<sup>22</sup>

Empowerment may be a very simple matter, for "treating families is not about science and technology (technique)." As Nichols reminds us, "It is an act of love."<sup>23</sup> There is wisdom in remembering that whoever welcomes "a little child," whoever does unto "the least of these," has ministered to a guest of celestial magnitude.

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<sup>22</sup> William C. Madsen, *Collaborative Therapy with Multi-Stressed Families* (New York: Guilford, 1999), 13.

<sup>23</sup> Michael Nichols, *Family Therapy* (New York: Gardner, 1984), 572, in Anderson, "Spirituality and Systems Therapy," in Burton, *Religion and the Family*, 94.

## Divine Destiny

We exist in an age of flux where diversity is cherished, where norms are challenged, and where opportunities abound, especially for those with disability. Technology has opened many avenues for people with disability, creating means for access, communication, and independence. Technology has done much good. Technology has also controversially invaded many sacred realms. Through technology, humanity has invented, produced, and stockpiled numerous modes for eliminating every being on the planet many times over. Catastrophes in nuclear, biologic, genetic, or cybernetic fields could obliterate creator mankind at any moment. Perhaps this is the end result of the deification of progress. Perhaps this is also the age in which God is about to “confound the human intellectual arrogance that tends to replace Him.”<sup>24</sup> Until recently, those with disability have been relegated to a marginal role in history, but in another world, a world where human power is conquered by human frailty, they may play a central role. For true strength realizes that “in our weakness, God’s power shows up best.”<sup>25</sup>

The prophetic voice of those with disability is beginning to be heard more clearly. That “still small voice” comes through here and there. Wolf Wolfensberger spoke of hearing such a voice. At a L’Arche retreat sat a man who would be classified as functioning in the “severely mentally retarded” range. He had lived in institutions all his life, had very little speech, was epileptic, and had a totally inexpressive face. At this retreat he sat all day with everyone, silently praying. Suddenly, about halfway through the day, he looked up, and though his speech was generally unintelligible, he spoke the

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<sup>24</sup> Wolf Wolfensberger, “The Prophetic Voice and Presence of Mentally Retarded People in the World Today,” *Journal of Religion, Disability, and Health* 4, no. 2-3 (2001): 15.

<sup>25</sup> Joni Eareckson Tada in Piepenbrink, “Secret to Joy,” 21.

only thing he said all day. Wolfensberger was almost knocked off his chair by hearing him state slowly, loudly, and clearly, “This is my body.”<sup>26</sup> The theological ramifications and prophetic significance of that statement are staggering.

The influence of the community of disability continues to expand. Struggling against huge odds, people with disability are sources of inspiration for life. When Joey Deacon, of Britain, was asked to write his autobiography, it was a challenge of massive proportions. Having lived in an institution for the mentally disabled for 42 years, he suffered from cerebral palsy and was barely able to care for himself in any way. For years, Joey mulled over the idea of writing a book, then at age 50, he put together a team to assist with the task. Ernie was the only person who could understand Joey’s speech. But Ernie could not write, so he interpreted Joey’s speech to Mike, who could only write slowly and laboriously. But Mike could not type, so he dictated to Tom, who could type with one finger, but not spell. Carefully, Mike spelled each word for Tom to type. The four worked for 14 months, averaging five lines a day, until *Tongue Tied* was published. The book merited global attention.<sup>27</sup>

Since those with disability have been neglected, even disparaged, creating a better environment for them could have astounding results. Hikari Oe was born with a herniated brain. Doctors told his parents that though a risky surgery might save his life, he would be, at best, severely mentally handicapped. They also tried to convince his parents to let him die, because the best they could hope for him was “a kind of vegetable existence.” Though an accomplished writer, baby Hikari’s father was already depressed because of a stagnating career, and wondered how they could endure a “monster baby.” They decided,

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<sup>26</sup> Wolfensberger, “Prophetic Voice,” 24.

<sup>27</sup> Ibid., 19.

however, to try the surgery. Hikari survived. Today he is epileptic, developmentally delayed, and visually and physically impaired. He is also a musical savant. Hikari's CDs have been bestsellers, and he has received one of the top musical awards in Japan.<sup>28</sup> But Hikari gave another gift to his father. Through the struggle of raising a son with disability, Kenzaburo Oe's life took on new meaning as he sought to give voice to his son who could not speak. His writing once again flourished. In 1994 he was awarded the Nobel prize for literature.<sup>29</sup>

Another recent example also comes from Japan. Hirotada Ototake was born with only stumps for arms and legs, but he was born into an intensely positive home. While a student at Japan's prestigious Waseda University, he published his autobiography. It became Japan's best-seller of the 1990s, and the country's number two book of the last half century.<sup>30</sup> Hirotada has inspired a nation and revolutionized the issues surrounding disability in Japan, a country which formerly kept those with disability in the closet.

Where will the community of disability take this world? What is the message it will convey? It is likely something we need to hear. As Wolfensberger explains, "if God is suddenly elevating retarded people to special and worldwide prominence, we may be witnessing the ultimate instance of God choosing the foolish to confound the wise, and there must be a terribly important message."<sup>31</sup>

All special needs families will not enjoy such grandeur or recognition. For some, the struggle to survive may last a lifetime. Not by any means will all children with

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<sup>28</sup>This fantastic site is a who's who of accomplished people with disability.  
[http://www.tampagov.net/dept\\_Mayor/mayors\\_alliance\\_for\\_persons\\_with\\_disabilities/famous\\_persons](http://www.tampagov.net/dept_Mayor/mayors_alliance_for_persons_with_disabilities/famous_persons)

<sup>29</sup> Dick Sobsey, "Hikari Finds His Voice," at [www.chninternational.com](http://www.chninternational.com)

<sup>30</sup> Mutsuko Murakami, "Handicap? What Handicap?" at [www.asiaweek.com](http://www.asiaweek.com), L.W. Milam, book review "No One's Perfect," at [www.ralphmag.org](http://www.ralphmag.org)

<sup>31</sup> Wolfensberger, "Prophetic Voice," 31.

disability become world renowned. Many will lie limply wherever they are laid and seem oblivious to this world. But the issue of progress is likely pointless; the foremost issue is that a family follows its call to enter into a higher reality and way of being. For nothing is accidental, but intense meaning can be found in everything. Most special needs families will never change the world in some grand fashion, but they may change their own world, and perhaps change the larger world on a plane that many do not see.

## APPENDIX

WARNING TO HELPERS:  
PHENOMENON OF THE DIVINE REVERSAL

On a recent trip to Japan, I was reminded of the things that really matter—the same things that Henri Nouwen contrasted, the horrid distortions of what we consider important in ministry as opposed to standing stark and vulnerable with love.<sup>32</sup> On my last day in Japan, I decided to heed a long-time, nagging sense that I should visit an old friend. I had first met Shotaro at our small church in an office building in the heart of Tokyo, not long after arriving in Japan with the noble ambition to spiritually impact the lives of future movers and shakers at the Ivy League Universities. But Shotaro was far from that. An adolescent in his early teens, he was not only mentally handicapped, but also blind. One day, church leaders asked if I would take time each Sunday to spiritually mentor Shotaro. Shamefully, I now admit that I was chagrined at the thought of spending my precious energies in such an unpromising endeavor. How little I knew of the spirit of Christ period.

Shotaro immediately attached himself to me. In the months that followed, I began to appreciate his simple trust, his faithful attendance to the Sunday preaching that was far above his capacity to grasp, and even the ghastly way he slurped his food at the noon meal. Shotaro was probably, at best, five years old mentally, and so the Bible stories and songs I taught him were simple and short. And he never forgot them. I heard he would sing songs like “God is so Good” over and over during the week. Shotaro was eventually baptized.

Nearly a dozen years passed. Shotaro was hospitalized, as his condition had continually declined. So before heading for my U.S. bound flight that day, I took a train to a remote part of Tokyo, and then walked a great deal distance to find the facility. Shotaro’s mother met me at the door and escorted me up to where he and his father waited. There lay my poor friend, emaciated like a victim of Auschwitz, with tubes protruding from his frail body. His joints bulged in comparison to his stick-like limbs. The playful personality was gone—he was merely hanging on.

I brought some sweets, which before he would have happily devoured, but his mother told me he could no longer eat. Besides that, he could no longer sit, or stand, or walk. And the mouth that used to laugh and joke could no longer talk. The one thing my little girl lacked was all he had, he could hear, but all else was lost. Inside a broken body, tightly shackled in a prison of darkness, lay a five-year-old little boy. I will never forget the look in his parents’ eyes—that look of indescribable agony. One cannot imagine what it’s like to watch the child you love slowly and painfully disintegrating.

I talked to him, I prayed for him, I felt like I was facing a stone wall. But then his father hoisted him up on the edge of the bed and braced him so we could sit side by side. Taking hold of his stiffened hand, of his permanently clawed outward fingers, I began to slowly sing our old tune, “Shu wa Subarashii” (God is so good, God is so good, God is so good, He’s so good to me). I almost lost it, but somehow got through singing those

<sup>32</sup> Henri Nouwen, *In the Name of Jesus: Reflections of Christian Leadership* (New York: Crossroad, 2000).



seemingly inappropriate words. Later, his parents wheeled him down to the entrance to bid me farewell. And then, as we parted, Shotaro managed to get one stiffened arm up to say good-bye. As I turned to go, I did lose it. My eyes streamed all the way back to the train station that sticky August afternoon. And inside, I cried out to God, "Why, why, why, must they suffer so?"

Originally, years ago, I went to Japan to impact some upcoming prime minister or CEO. However, I ended up touched by the simple and inconspicuous life of a boy struggling with disability. In a situation similar to Nouwen's, I found myself healed by one "who had few or no words and considered, at best, marginal to the needs of our society."<sup>33</sup> Who was the real minister in this story? That is humiliatingly obvious. The simple and vulnerable broken boy taught the highly trained, educated, and mistakenly motivated missionary. I am immensely grateful and proud to have been under the tutelage of Shotaro. And last May, Shotaro got a new body.

When asked to write words for his memorial service, I penned the following lines:

#### Inspiration

Your body bore the stain  
Of a world soiled with pain  
You carried the greater share  
Of suffering others might not bear

Reminder of an innocent Son  
Hanging on jagged wood  
Drained of precious blood

Your body carried the light  
Of a world filled with delight  
Relishing the smallest joy  
Grateful sermon in a little boy

Reminder of a realm to come  
Finally seeing all will know  
The gift of life above, below.

Thank you my friend.

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<sup>33</sup> Nouwen, *In the Name of Jesus*, 11.

## AUTHOR PROFILE

Andrew Leon Meeko is the father of a special needs child—his daughter Sophia was born profoundly deaf. Andrew and his wife, Junko, along with their four children, fellowship in a deaf church in Japan. Andrew is a second-generation missionary to that country. Part of the family's ministry has centered on pioneering Campus Crusade for Christ's FamilyLife Japan, which specializes in strengthening marriages and homes. Besides speaking on family issues nationwide, Andrew has written for numerous publications. His writing includes the book *Shorai no Tamashii: Atarashii Jidai no Tame no Kosodate* (Souls of the Future: Parenting for a New Era). He has a B.A. in Geology and a B.A. in Japanese Language from the University of Hawaii, and a M.Div. from Western Seminary in Portland, Oregon.

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